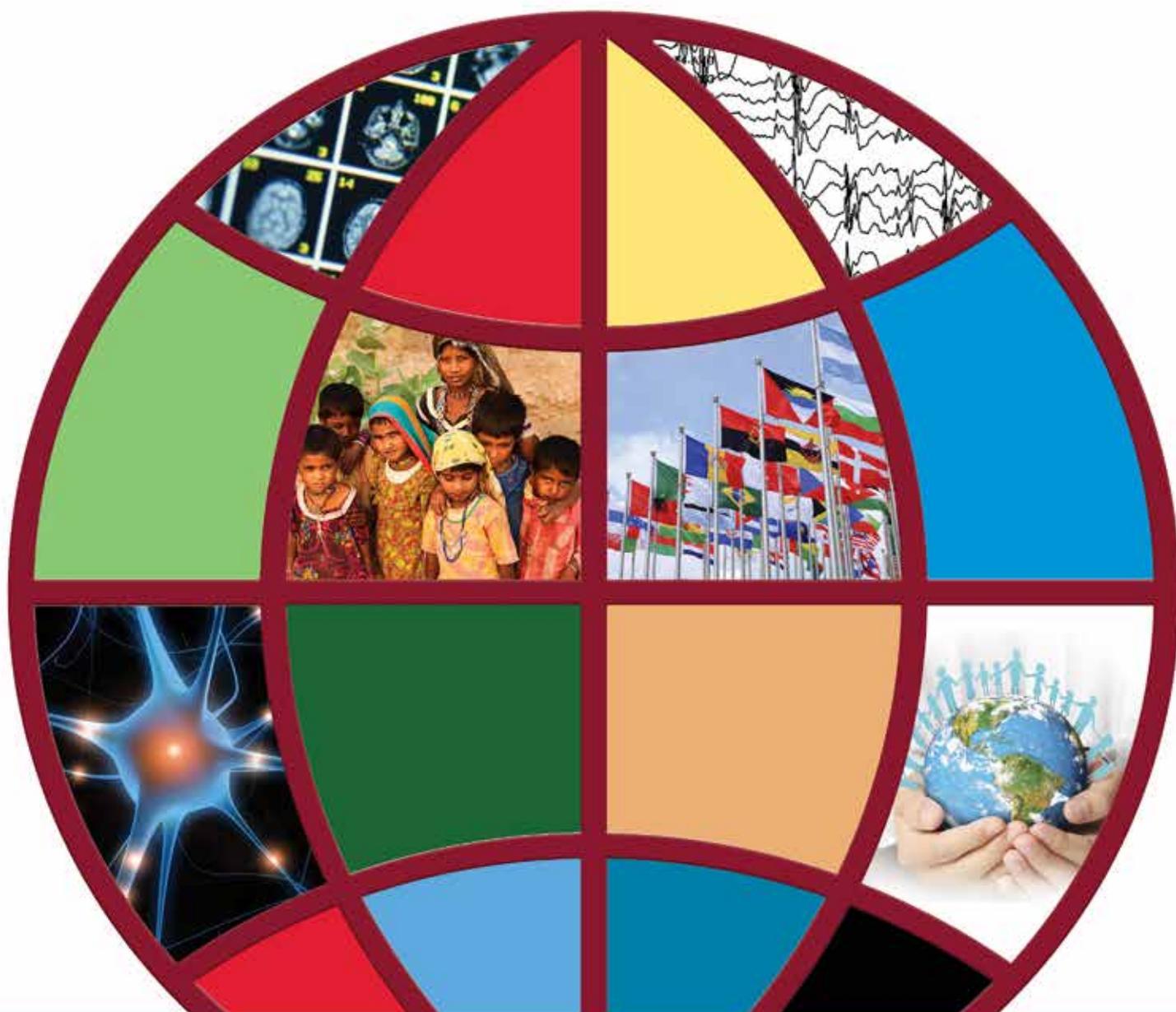


A Global Agenda

2016 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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PRESIDENT'S REPORT



Emilio Perucca

As my term as President of ILAE comes to a close, it is appropriate to take a pause and reflect on what has been achieved over the last four years, and to highlight the priorities that should guide our activities in the future. The League is a privileged organization that can count not only on the dedication of its officers and personnel, but also on the contribution of hundreds of members of Commissions and Task Forces, and thousands of professionals who participate in the activities of our 114 national Chapters. None of the achievements described below could have materialized without the commitment and perseverance of these individuals.

The activities of the League during the 2013-17 term were guided by the goals set out by the Strategic Plan implemented in 2009 (<http://www.ilae.org/Visitors/Documents/StrategicPlan-FinalJuly-09.pdf>), and can be described by reference to the key priority areas identified by the Plan.

Serving as the premier international resource for epilepsy knowledge

Since the League's inception, ILAE Commission and Task Force Reports have been a valuable resource to epilepsy professionals, assisting them in improving diagnosis and management based on the best available evidence. During the 2013-17 term, a total of 33 ILAE Commission and Task Force Reports have been published in our journals and received with great interest, as testified by the high number of citations and downloads. The list of these publications, which cover a wide range of topics, can be found in the Secretary General's report.

In 2013, the Executive Committee adopted a new procedure for the approval of papers that represent the 'official' position of the ILAE, i.e. documents that are intended to provide a common language or set of definitions for the international epilepsy community (e.g. defining epilepsy, defining specific syndromes, classification) (<http://www.ilae.org/Visitors/Documents/Guideline-PublPolicy-2013Aug.pdf>). These papers are initially reviewed by the Executive Committee for overall approval of concept and content, and then submitted to *Epilepsia* for peer review and placed simultaneously on the web for public comment for a period of two months. All comments received are then addressed and incorporated as appropriate by an *ad hoc* Task Force, prior to final approval by the Executive Committee as the ILAE position. This procedure ensures that the League's position papers reflect not only knowledge of a selected group of experts, but also the input of our entire constituency worldwide.¹

The first position paper approved through this process was the practical (operational) clinical definition of epilepsy, published in 2014.² This was

followed in March 2017 by the final position papers on the classification of epileptic seizures³ and the classification of the epilepsies.⁴ These position papers, which are available via open access in the *Epilepsia* website (<http://onlinelibrary.wiley.com/doi/10.1111/epi.13709/epdf>; <http://onlinelibrary.wiley.com/doi/10.1111/epi.13670/epdf>) represent the culmination of a massive effort that has been ongoing within our community for over a decade, and provides a modern ILAE framework for terminology, definition and classification of epilepsy and seizure types. To assist the user in the application of these concepts, the ILAE Commission on Classification and Terminology has also prepared an instruction manual that includes a valuable glossary and examples based on seizure descriptions from everyday clinical practice⁵ (<http://onlinelibrary.wiley.com/doi/10.1111/epi.13671/epdf>).

A related initiative aimed at improving diagnosis of seizure types and epilepsy syndromes is the cutting-edge online diagnostic manual of the epilepsies, *epilepsydiagnosis.org* (www.epilepsydiagnosis.org). The manual was conceived and developed by the Diagnostic Manual Task Force of the previous ILAE Commission on Classification and Terminology (2009-2013), in partnership with eResearch at the University of Melbourne. It was launched formally in September 2014 and is being constantly updated thanks to the wonderful dedication of Kate Riney and her team. *Epilepsydiagnosis.org* harnesses the power of the internet to present the complexity of the large amount of new information now available about the epilepsies and their etiologies in a manner that is concise, current, and accessible to a global audience. It is as relevant to those in primary and secondary health care settings as it is to those in tertiary epilepsy practices. As an indication of the success of this initiative, in the last quarter of 2016, the manual had an average of 10,200 users per month engaging in 12,800 visits to the website, for an average of 7.5 minutes per visit, with 44,000 page visits each month.

The exponential increase in the amount of information becoming constantly available is a challenging experience for physicians who strive to remain updated on the latest developments, and to base their clinical decisions on the best available evidence. Well-structured clinical guidelines provide an important tool in condensing large amount of information, assessing the quality of the evidence based on transparent criteria, and applying it to practical recommendations for rational diagnosis and management. Although in the past the League has been involved in the production of guidelines, it was only in the present term that the ILAE Task Force on Guidelines, led by Nathalie Jetté, developed rigorous rules and procedures to be followed when preparing ILAE guidelines in the future.⁶ In parallel, the Task Force on Guidelines also conducted a systematic search of currently existing clinical guidelines⁷ identifying major gaps which,

PRESIDENT'S REPORT *(continued)*

hopefully, our organization will be able to address in the near future.

During the current term, the ILAE has increasingly potentiated its educational activities through a greatly improved website, a consolidation of VIREPA (distant education) courses, and an expanded range of educational courses and training fellowships, run mostly through our Regional Commissions and related educational academies. After two successful International Epilepsy Congresses (IECs) in Montreal (2013), and Istanbul (2015), preparations have been completed for the next IEC, which will take place in Barcelona on September 2-6, 2017. Equally successful Regional Congresses took place during the same period in Europe, the Asian-Oceanian region, the Eastern Mediterranean region, Africa, and Latin America. For North America, Regional Congresses were organized in 2014 and 2016 jointly with the American Epilepsy Society. Each of these congresses incorporates a vast and diverse educational program, especially targeted to our younger members. Participation of younger colleagues in ILAE-organized educational activities has been supported by comprehensive bursary programs and markedly discounted registration fees for participants under 40 years of age. In parallel, mentorship training programs have also been established to promote career development for young leaders engaged in epilepsy care as well as research. As part of another mentorship initiative, young professionals have also been included in the membership of ILAE Commission and Task Forces.

The League's long-term policy of strengthening collaboration with other professional societies in areas related to advocacy and education has been actively pursued during the 2013-17 term. In particular, a most gratifying partnership has been established with the World Federation of Neurology (WFN). Examples include the organization of joint sessions at ILAE and WFN congresses; the co-funding by the two organizations of epilepsy-related research projects; strong WFN support to the initiative that led to the WHA Resolution on Epilepsy (see below), and the subsequent dedication of 2015 World Brain Day to epilepsy; excellent collaboration in the working group assisting WHO in the finalization of ICD codes; and the hosting of the General Assembly of WFN delegates at the venue of the European Congress of Epileptology in 2016. A strong collaboration has also been built with the European Academy of Neurology (EAN), including the organization of joint congress sessions, the stipulation of a memorandum of understanding on joint production of guidelines, and the publication of a consensus paper⁸ on the use of valproate in girls and women of childbearing potential within the framework of the 2015 restrictions imposed by the European Medicines Agency. On the strictly educational side, a close collaboration is being finalized with the British Pediatric Neurology Association (BPNA) for the implementation of joint courses on the diagnosis and management of epilepsy in infancy and childhood.

The last four years also witnessed new exciting developments in the League's publication portfolio, and I am grateful to the editors of our journals for making such developments possible. *Epilepsia* continues to be the most prestigious epilepsy journal for publication of original research articles and scholarly reviews, and its impact factor has steadily risen from 3.91 in 2012 to 4.70 in 2017. In 2013, the ILAE acquired *Epileptic Disorders* as its journal dedicated primarily to education. Finally, in September 2017, the League launched *Epilepsia Open*. As I explained in an accompanying commentary⁹, *Epilepsia Open* is a response to a call from our community, which believed that our pre-existing publication portfolio was insufficient to host the ever-increasing amount of high-quality epilepsy research being conducted throughout the world. At the same time, with the ongoing shift from subscription journals to open access journals, the League needed to invest in the open access model to maintain its leadership in the epilepsy global publication arena. By publishing in *Epilepsia Open*, authors can ensure that their research is readily accessible to the entire scientific community without any subscription fee, thereby enhancing the global visibility of their work and, ultimately, their citation index. As a further advantage, the new journal will make such research available free of charge to people with epilepsy, their families, and other lay readers who would otherwise have no means to access it.

Serving as leader for optimal, comprehensive epilepsy care

Because of its role as the leading organization in promoting epilepsy knowledge and epilepsy education, the League is in a privileged position to advance epilepsy care worldwide. To do so effectively, the League must establish partnerships with key stakeholders at national and international levels, a goal that can be leveraged by collaborating with its Chapters in 114 countries. Historically, the League has worked effectively with its sister organization, the International Bureau for Epilepsy (IBE), and with the World Health Organization (WHO). The ILAE-IBE-WHO Global Campaign against Epilepsy, established in 1997, has been an invaluable tool to raise awareness about epilepsy as a global problem, and to implement a number of demonstration projects to reduce gaps in diagnosis and treatment, particularly in low- and middle-low-income countries.¹⁰ The decision by the League and Bureau to jointly establish and promote an International Epilepsy Day, to be celebrated annually on the second Monday of February, starting from 2015, represents an added initiative to raise global awareness.¹¹

Despite the success of these initiatives, the need for a renewed effort to raise the visibility of epilepsy and to trigger concrete actions on a planetary scale was broadly felt within our community. To this end, as early as 2013, ILAE and IBE started to work together with many Chapters and Associations in order to sensitize national governments to the importance of bringing the

PRESIDENT'S REPORT *(continued)*

many unmet needs of epilepsy to the attention of the World Health Assembly (WHA). It was in this context that, in late 2014, the People's Republic of China made a formal request to WHO to have epilepsy included in the agenda of the 136th WHO Executive Board meeting, which was in charge of developing the agenda for the 2015 WHA. The fact that this important step was taken by the People's Republic of China was not by chance. In fact, since 2004, the Chinese government has played a pioneering role in addressing the epilepsy treatment gap by conducting, in conjunction with WHO, ILAE and IBE, one of the most successful projects in the history of the Global Campaign, demonstrating the cost-effectiveness of reducing the epilepsy treatment gap. This project had resulted in an excellent collaboration between the Chinese health authorities and the China Association against Epilepsy (CAAE), which had been established a few years earlier by Dr. Shichuo Li, a former Director of the WHO Executive Board. The preparation of a draft Resolution on the Global Burden of Epilepsy by the People's Republic of China, jointly with the Russian Federation, resulted in an intensive mobilization of the joint ILAE-IBE Global Outreach Task Force, led by Alla Guekht and Mary Secco. The aim was to sensitize our constituencies and national health authorities worldwide about the importance of supporting the initiative. The response from ILAE Chapters and IBE Associations was overwhelming and partner organizations, including WFN and Health Action International, joined forces in supporting the effort.

The historical moment came on May 26, 2015 when the Resolution on Epilepsy was unanimously approved by the WHA. During the process, delegates from a total of 42 countries from five continents stood up making strong statements in support of the Resolution, in some cases also on behalf of other nations (Table 1). More details about these events and the importance of the Resolution are provided in a comprehensive article in *Epilepsia*.¹² In short, the Resolution urges all Member States to implement specific measures against the burden of epilepsy, including (i) the promotion of epilepsy awareness and education; (ii) the establishment of national healthcare action plans for epilepsy; (iii) the integration of epilepsy diagnosis and management into primary health care; (iv) the implementation of strategies to prevent epilepsy and to improve access to medicines; (v) the allocation of resources to support epilepsy research; and (vi) the engagement of civil society and other partners in these actions. The Resolution also instructs WHO to conduct specific activities to support and monitor the implementation of the above measures. Concrete follow-up actions along the recommendations made by the Resolution are already taking place in several countries, often in consultation with ILAE and IBE national constituencies. In many regions, these actions are facilitated by earlier national and international recommendations and guidelines, including the European Parliament's Written Declaration on Epilepsy^{13, 14}, the U.S. Institute of Medicine Report¹⁵, and the Pan American Action Plan on Epilepsy.¹⁶

Table 1. List of countries whose delegates made official statements in support of the Resolution on the Global Burden of Epilepsy at the 136th meeting of the WHO Executive Board and/or at the 68th WHA.

Albania	Indonesia	Romania ¹
Argentina ¹	Iraq ⁴	Russian Federation ¹
Australia ¹	Islamic Republic of Iran ¹	Saudi Arabia
Azerbaijan	Italy ¹	Saudi Arabia
Bahrain	Japan ¹	Suriname
Benin ²	Lebanon	Swaziland
Brazil ³	Lithuania	Taiwan (Chinese Taipei)
Canada ¹	Malaysia ¹	Tanzania
Czech Republic	Maldives ¹	Thailand ¹
Democratic Republic of Congo ²	Malta ¹	Timor-Leste
Egypt ⁴	Nepal	United Kingdom ¹
Georgia ¹	Panama ¹	United States of America
Ghana ¹	People's Republic of China ¹	Uruguay ⁵
Greece ¹	Poland	Venezuela ¹
India	Republic of Korea	

¹Countries which co-sponsored the Resolution.

²Delegate also spoke on behalf of the 47 Members of the African Region.

³Delegate also spoke on behalf of the 35 Member States of the Region of the Americas.

⁴Delegate also spoke on behalf of the 21 Member States of the Eastern Mediterranean Region.

⁵Delegate also spoke on behalf of the 12 Member States of Union of South American Nations.

The ILAE recognizes that, even when the best diagnostic and therapeutic facilities are available, about one-third of people with epilepsy fail to achieve seizure freedom and a good quality of life. More efficacious treatments are sorely needed, including treatment that could have an impact on the underlying course of the disease rather than just suppressing its symptoms. To address this important gap, the League is continuously spurring initiatives to promote high-quality epilepsy research. A major project in this respect is being conducted by the joint ILAE-AES Task Force on Translational Research, which already produced several landmark guidance documents on methodology to improve standards of preclinical epilepsy research.^{17, 18}

With respect to clinical research, the League has established, through the work of its Drug Regulatory Task Force, an effective interaction with regulatory agencies across the globe, including the U.S. Food and Drug Administration (FDA), the European Medicines Agency (EMA) and the Japanese Pharmaceuticals and Medical Devices Agency (PMDA). Communication of the Task Force with these agencies provides the opportunity to contribute expert advice on issues related to the development of drugs and devices

PRESIDENT'S REPORT *(continued)*

and the terminology to be used in regulatory documents, such as prescribing information. This collaboration included interactive sessions at ILAE congresses with participation of representatives from regulatory agencies to discuss topics such as approval of antiseizure drugs for pediatric populations, requirements for monotherapy approval, and the hurdles involved in the licensing of drugs for status epilepticus. Other initiatives related to epilepsy research include the publication of two commission reports on research priorities from a regional perspective^{19, 20} and a major ongoing effort with other key stakeholders to stimulate multinational funding of ambitious research projects which could only be conducted through broad scale international collaboration. The latter initiative is described in more detail in the Report of the joint ILAE-IBE Global Research Priorities and Advocacy Task Force. As described earlier in this report, a number of actions have also been taken to stimulate the participation of young scientists in epilepsy research. This includes creation of prizes and congress presentations for the best research papers in both basic and clinical epileptology published by young scientists in *Epilepsia*.

Ensuring the organizational and financial viability of the League

As discussed in many sections of this Annual Report, in recent years the League has taken significant steps to improve its organizational structure and operations. Important challenges that had to be addressed include (i) advances in information technology, which require adjustment and investment in our communication and educational activities; (ii) the increasing expansion of the open access model for the publication of scientific research, which threatens the viability of subscriber-based journals; and (iii) sweeping changes in economic and regulatory scenarios, which resulted in a progressive and drastic reduction of revenue from ILAE congresses. These challenges have obvious implications for the financial viability of the League. As discussed in detail in the Treasurer's report, the ILAE was able to build over time a modest endowment fund which is especially designed to generate revenue from investments and permit the long-term sustainability of activities at the current level of expenditure. It is thanks to this model that, despite a steady decline in revenue, the League has been able not only to maintain, but in many instances also to increase, its support to educational activities, to the upgrading of the website, and to the work of Commissions and Task Forces. As an additional positive development, during the 2013-17 term, the League negotiated in favorable terms new contracts with our publishers, with Association Resources (the organization that provides administrative services to us), and with Chancel, our professional congress organizer. These developments were skillfully coordinated by Sam Wiebe, our Treasurer and President-Elect, with invaluable support from our staff at Associate Resources and Chancel, and from the members of the Budget Review Committee, the Finance Committee and the Financial Advisory Committee.

The latter includes a team of external advisers with top financial expertise who dedicate their time pro bono to provide guidance to the League on the optimal allocation of its investment portfolio.

Implementing thought-provoking and innovative concepts that advance the League's vision and mission

Many of the activities described above to advance the League's vision and mission required the application of thought-provoking concepts and ideas. For this, I feel indebted to the large number of dedicated professionals who inspired the League in the development of new tools and initiatives. Among the many such initiatives, I would like to name at least one, and that is Epilepsy in Wikipedia, a project which was born out of an idea of Sam Wiebe's. Wikipedia is by far the most widely accessed resource to gather information on any aspect of knowledge, including epilepsy, and it is used not only by the general public, but also by medical students, primary care physicians and specialists. Ensuring that information on all aspects related to epilepsy in Wikipedia is accurate and updated timely determines how epilepsy is perceived, diagnosed and treated in all parts of the globe. Based on this, the League has reached an agreement with Wikipedia's editorial office to take on responsibility for the review and update of all epilepsy-related content in this web-based resource. Dr. Günter Krämer and a team of associate editors have been recently appointed to implement this challenging project.

Conclusions

The four years that I spent as President of the League have been hectically busy, but immensely gratifying to me. By far the greatest source of gratification has been the continuous support of an incredible number of volunteers who dedicate their time on Commissions and Task Forces to advance our mission and, ultimately, improve the lives of people with epilepsy. The League is truly blessed to be able to count on such people. I also wish to express my gratitude to all the members of the Management and Executive Committees, including the editors of our journals, for their continuous support and inspiring collaboration; to Priscilla Shisler, our Administrative Director, Donna Cunard, our Financial Officer, and Maddalena Milani, my Personal Assistant, for their invaluable help in the day-to-day running of operational activities; to Richard Holmes and his wonderful team at Chancel for their excellent work in the organization of our congresses, and the running of the ILAE Chapter Services office. During my term, I was also fortunate to be working side by side with a highly dedicated IBE President, Athanasios Covanis, and a very supportive IBE team. The relationship between ILAE and IBE, and between our organizations and WHO, has never been stronger. Without the contribution of all these colleagues and hundreds of volunteers working in our Chapters

PRESIDENT'S REPORT *(continued)*

throughout the world, none of the achievements listed in this report would have materialized. To all, a truly heartfelt thank you. Very special thanks also go to my wife, Tita, who for many years so patiently tolerated my being away from home for long periods of time, and my being always busy when at home to catch up with never-ending backlogs of work.

To my successor, Sam Wiebe, and to the 2017-21 Executive Committee, all my best wishes for a highly successful new term. The League is in great hands with the new team, and surely will continue to thrive for many years to come.

Emilio Perucca
President

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TREASURER'S REPORT



Samuel Wiebe

1. Preamble

It has been challenging and exciting to serve as the League's treasurer during this term. As described in the reports of the President and the Secretary-General, the League is a large organization with a worldwide diverse constituency, multiple international and regional partnerships, and an expanding list of global initiatives.

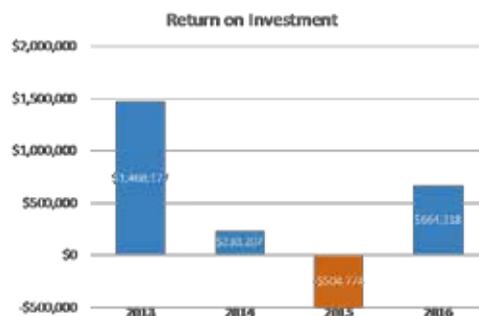
Under the statutes of the ILAE, the main role of the Treasurer is "to ensure the integrity of the fiscal affairs of the ILAE." This includes ensuring that ILAE accounts are maintained according to international standards, overseeing annual fiscal audits, being responsible for any financial activity delegated to contractors or external entities, developing an annual budget for approval by the Finance and Executive Committees, presenting for approval to the General Assembly an annual financial report, the financial aspect of the League's Journals, exercising prudence in maintaining the assets of the ILAE, monitoring the financial performance of the organization, and overseeing long-range financial planning.

2. Financial Overview

The ILAE's two main sources of revenue are its International and Regional Congresses, and its Journals. Its two main expenditure categories are Operations/Administration, and activities related to its mission and goals. The ILAE is also building an endowment fund designed to generate revenue from investments which will allow the organization to carry out its mission.

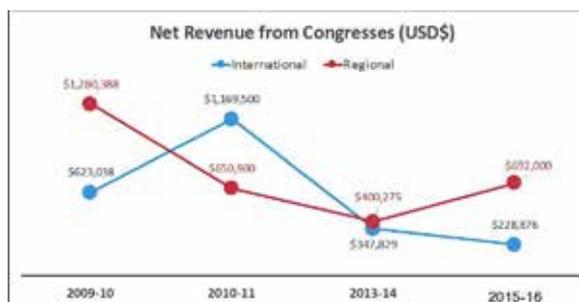
3. Investment Portfolio

The investment policy of the League includes the development of a USD \$20 Million endowment whose purpose is to support the League's activities in a sustainable manner by drawing on the returns on investment of this endowment. At present, the main capital of the endowment is at USD \$16 Million, or 80% of the target. Revenue on the League's investments suffered in 2014 and particularly in 2015 due to poor performance of financial markets. However, it showed recovery again in 2016 (Figure).



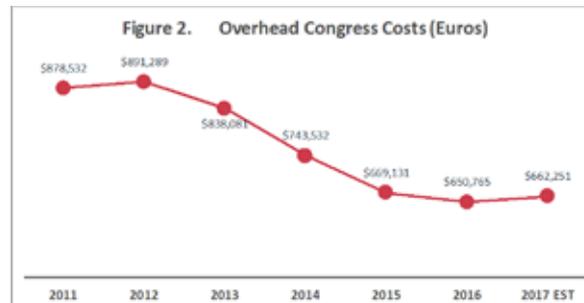
4. Congresses

As stated in previous reports from this Treasurer, revenue from Congresses has declined steadily for the last eight years and we saw its lowest point in the years 2013-2014, when I started my role as Treasurer (Figure). The projected revenue for the 2017 International Congress is similar to the previous Congress.



TREASURER'S REPORT *(continued)*

Our congresses have become more efficient. With the able assistance of Richard Holmes' team (IDM), we have increased efficiencies, cutting administrative costs (Figure 2), making better use of our congress structure, obtaining substantial discounts from venues, and creating incentives for external support.



5. Some salient tasks: 2013-2017

During this term, the financial position of the ILAE was strengthened through the following actions:

1) Revised and Amended the Investment Policy

Guided by the Finance and Advisory Committees, the Executive Committee approved our proposal for revisions to the ILAE investment policy. This document stipulates the general roles and procedures related to financial management of the League's assets and its ability to accomplish the League's Mission. The amendments included a revision of the endowment goals to a target of \$20 Million USD, specification of asset allocation, timelines for reporting, and delineation of a spending policy.

2) Implemented a Spending Policy for ILAE

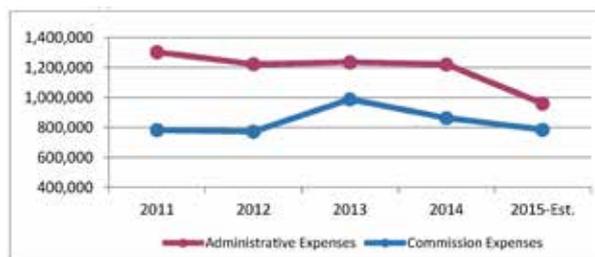
The Executive Committee approved our recommendation to adopt a Total Return Policy in which annual spending would be composed of income or capital gains in combination. The policy guides the amount that can be withdrawn from the principal investment to support the League's mission in a sustainable manner. This was particularly important in order to address poor financial market performance, a decrease in revenues and an increase in ILAE activities. The spending policy allowed for withdrawing an amount of funds equivalent to 60% of the average return on investment in the previous eight quarters, adjusted for inflation. This policy served us extremely well, because it allowed us to calibrate our expenditures in line with our revenues. Most importantly, it demonstrated the enormous value of the endowment fund, from which we drew funds during several budget cycles to accommodate low revenues while supporting the requests for funding from our Commissions and Task Forces.

3) Adopted a Balanced Budget Policy

On the recommendation of our Finance Committee, we adopted a policy whereby the annual budget should be balanced over a two-year period. This allowed the flexibility to allocate sufficient resources to our Commissions and Task forces while accepting a deficit budget which would be balanced in subsequent cycles.

4) Increased Operational Efficiencies

As shown in the Figure, we decreased operational/administrative expenses by 25%, while maintaining our level of support for Commissions and Task Forces.



TREASURER'S REPORT *(continued)*

5) Negotiated Contracts for Publishers of ILAE Journals

A request for proposals for publishers of the League's Journals commenced in 2014. A publisher was sought to publish *Epilepsia*, distribute *Epileptic Disorders*, and develop and publish our new Open Access Journal *Epilepsia Open*. We retained Kaufman, Willis and Fusting (KWF) as the academic publisher services consultant to assist us in the process. After a careful assessment of the top bidding publishers, a very favourable contract was signed with Wiley for the three journals as described above. A contract was also renewed with John Libbey Publishers to continue publishing *Epileptic Disorders*, while Wiley would act as distributor of this journal.

6) Renewed Contract with Association Resources

Association Resources (AR) is the organization that provides administrative and operational services to the ILAE. The contract with AR was evaluated and the decision was made to propose to the Executive Committee to renew the contract with AR for a period of three years, from 2016 to 2019.

7) Reviewed Financial Aspects of Agreement with Chancel

Chancel is the organization in charge of International Congresses for ILAE and IBE, which are its only clients. The contract was renewed for a period of five years in 2016. The Treasurer reviewed the accounts and financial aspects of the new contract with Chancel.

6. Teams and People

As an academic neurologist/epileptologist, I would have been utterly unable to discharge these obligations without the support of our outstanding staff in finances and accounting, first and foremost Donna Cunard; but also Priscilla Shisler our Administrative Director, and Eve Bolger and Jane Haggerty accounting in the Dublin Chancel office. I was fortunate to receive sound guidance from our dedicated Finance Committee members, and we were able to see the big financial picture and plot a course for the League's finances thanks to the wisdom of a devoted group of international financiers that constitute the Finance Advisory Committee. To everyone in these groups I owe a large debt of gratitude, and I extend, on behalf of the League a heartfelt thank you.

The work of the ILAE Treasurer is by its very nature performed in teams. I was immensely fortunate to work closely during this term with highly skilled people in the following teams:

Finance Committee:

Samuel Wiebe (Canada, Chair), Gary Mathern (USA, Past Chair), Jean Gotman (Canada), Emilio Perucca (Italy, ILAE President), CT Tan (Malaysia), Torbjorn Tomson (Sweden)

Finance Advisory Committee:

Sergio Bruno (Italy, Chair), Irwing Engelman (USA), John Heffer (USA), Fred Lado (USA), Derek Sach (United Kingdom)

Budget Review Committee:

Michel Baulac (France, Chair), Andrew Cole (USA), Reda Ouazzani (Morocco), Cigdem Ozkara (Turkey), Lynette Sadleir (New Zealand), Elza Marcia Yacubian (Brazil)

Finance and Administration:

Donna Cunard (ILAE Financial Officer), Priscilla Shisler (ILAE Administrative Director), Eve Bolger (IDM Accounting), Jane Haggerty (IDM Accounting).

As an elected officer of the ILAE, I would like to thank our constituency for entrusting me with managing the League's finances during this term. It has been a pleasure and a privilege to serve in this capacity.

Samuel Wiebe
Treasurer

SECRETARY-GENERAL'S REPORT



Helen Cross

It has been a privilege to serve as Secretary-General over the term 2013-2017. This has involved consolidation of responsibilities including the oversight of official records of the ILAE, promotion of chapter development, as well as the processing and maintenance of reports of Commissions and Task Forces, submitting them for approval to the Executive Committee.

Two further chapters, Myanmar and Belarus, were definitively accepted at the ILAE General Assembly during the 31st International Epilepsy Congress in Istanbul in September 2015. Formal acceptance increased the number of League chapters to 115. Several additional countries are now going through the process so we expect this to increase further in the near future.

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 me, with membership including all regional commission Chairs and Tatsuya Tanaka. A process that applies to all regions was agreed on, and the Bylaws changed accordingly. 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. In addition, there have been frequent requests for ILAE endorsement of Congresses and scientific meetings, not necessarily fully organized by Commissions or Chapters of the League. Guidelines have therefore been formulated and agreed upon, now available on the ILAE website, for submission and assessment for support from Regional and Topic orientated commissions (<http://www.ilae.org/Visitors/Congress/congressinfo/EndorseProcedure-2014.pdf>).

Many reports have been formulated and published by Task Forces and Commissions on behalf of the League over this term. 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>) were developed at the beginning of the term. In order to streamline the process, we formed a new Publication Task Force which advises the Executive Committee on the standard of a submitted document and recommend which of our three journals may be suitable for publication. A new system has also been applied to ensure feedback and comment from the membership is taken into consideration on position documents produced by the League. This has been tested on two specific position papers finalized this term; the Operational Classification of Seizure Types, and a Position Paper of the ILAE Commission for Classification and Terminology as follow-up to the 2010, and 2013 publications, both of which are now in press in *Epilepsia*. Further to these, a total of 28 papers have been approved for publication so far over this term. Those in press at the time of this report are listed below.

The League has collected much archived material over time; during this term we have utilized the Wellcome Trust library to archive collected material to date. Under the supervision of Simon Shorvon (to whom we are extremely grateful), an archivist was employed who has done an excellent job in fully cataloguing material; a full report was produced and the catalogue is fully available on the Wellcome Trust website. It is clear there will be other material, and a system for collecting such material and disseminating awareness of their availability is being discussed. This includes a policy with regard to digital archiving.

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

Helen Cross
Secretary-General

SECRETARY-GENERAL'S REPORT *(continued)*

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SECRETARY-GENERAL'S REPORT *(continued)*

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VICE-PRESIDENT'S REPORT



Tatsuya Tanaka

Following a four year term (2009-2013) of the First Vice President of ILAE, it has been almost four years since the beginning of the current Management Committee at the Montreal International Epilepsy Congress in 2013. In these four years, it has been a privilege for me to participate in the League leadership during this exciting period. As the scope and membership of the League expanded, it became clear that there was a real need to represent our constituency better, and the first and major step the League took was amending its constitution to ensure participation of all regions in the governance of the League at the highest level with membership to the Executive Committee and the Management Committee.

When I was First Vice President in the previous Executive Committee (2009-2013), a Constitution Task Force was created to amend the Constitution and Bylaws under the direction of President Nico Moshé because no amendment was performed during long period of time. The newly amended constitution was ratified by the General Assembly at the Rome International Epilepsy Congress in 2011. Thus, ILAE President (Emilio Perucca, 2013-2017 and Samuel Wiebe, 2017-2021) were successfully elected. New members of the Management Committee (2017-2021: Helen Cross, Edward Bertram and Alla Guekht) were also successfully elected. These new guides for League function assured that all regions would be represented and have a voice in League governance.

One of the important constitutional changes 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 ensured that the voice of each region is more reflective of the wishes of the chapters. The elected Regional Chairs are now members of the Executive Committee, which improves communications not only between the leadership of the League and the regions but also across regions, for the benefit of the ILAE as an international organization. It's a very positive change that I have experienced first-hand because I served under the old and new Constitution and Bylaws. However, because the rules, conditions and history of each region are very different from each other, we have completed the process of harmonizing the election process for all regions according to the ILAE Constitution and Bylaws in order to apply for each regional election by the new Election Task Force (Helen Cross, Chair). New Bylaws will be applied for the election of ILAE regional chairs (2017-2021).

Collaboration with the work of Commissions.

As a member of the EC Liaison Officer of the Neuropsychiatry Commission and Neurosurgery commission, an EC Liaison Officer of the Commission of Asian Oceanian Affairs, many collaborative works were performed during past four years. Especially, programming of the 12th Asian-Oceanian Epilepsy Congress in Bali 2018 as a member of Scientific Organizing Committee was already started.

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.

Finally, I want to express many thanks to members of the Management Committee and Executive Committee, as well as all ILAE members for their kind and continuous support and help during my two ILAE terms for eight years.

With my best wishes,

Tatsuya Tanaka
Vice-President

ELECTIONS COMMISSION REPORT



Solomon Moshé

During 2016, the election process for the new President and members of the Management Committee took place. Dr. Sam Wiebe was elected president of the ILAE for the years 2017-2021 and Drs. Ed Bertram, Helen Cross and Alla Guekht were elected as members of the Management Committee. The subsequent elections will take place in 2017 for the completion of the members of the Executive Committee/Regional Chairs, as well as the members of the Regional Commissions. We wish to thank Mr. Gus Egan for effectively assisting the Committee in the election process.

Respectfully submitted,
Solomon L. Moshé
for the Election Commission
(Peter Wolf, Pete Engel,
CT Tan, Giuliano Avanzini,
Natalio Fejerman and Paul Kioy).

EPILEPSIA REPORT



Gary Mathern



Astrid Nehlig



Michael Sperling

In 2016, *Epilepsia* had another successful year. In bibliometric terms, in 2016 *Epilepsia* was ranked 33rd of 193 journals in the Clinical Neurology category, had an Impact Factor (IF) of 4.706, and an Eigenfactor of 0.04. The *Epilepsia* IF has been steadily increasing over the last four years and increased further from 4.571 in 2014 to 4.706 in 2015/2016. It remains higher than that of any of the other epilepsy sub-specialty journals, with the exception of *Epilepsy Currents*. The objective for the coming years is to try to increase the impact factor further, and to reach at least the magic number of 5.0 which will attract more interest and even higher quality publications, mainly in basic science especially from Europe.

Volume 57 (calendar year 2016) comprised 2,083 pages, which included twelve regular monthly issues, and we also published the following supplements:

S1: SUDEP: Time for Prevention – Evidence and Clinical Translation – Lina Nashef, guest editor

S2: Special Issue: 12th European Congress on Epileptology, Prague, Czech Republic, 11-15 September, 2016

S3: Hypothalamic Hamartomas – Jean Régis and Jack Kerrigan, guest editors

During 2012, *Epilepsia* received over 1,400 submissions and accepted ~ 22% of peer-reviewed manuscripts. The accepted/published manuscripts can be categorized as follows: Reviews (including historical reviews) = 32; Full-Length Original Research reports = 203; Special reports (ILAE Commission reports) = 4; Brief communications = 50; Gray Matter material not peer-reviewed, including letters, commentary, workshop reports, and various communications = 26. 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 terms of circulation and readership, there were 583 institutional subscriptions to *Epilepsia* (a slight decline from 2011), with over 4,000 institutions having licensed access to the Journal. *Epilepsia* also participated in the HINARI program to provide the Journal free of charge to over 3,800 libraries in developing world countries. In 2012, there were over 1,300,000 full-text downloads from *Epilepsia*, reflecting a 39% increase over the previous year.

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

EPILEPTIC DISORDERS



Alexis
Arzimanoglou



Jean Aicardi

The members of the team of Associate Editors and the Editorial Board have recently been revised for 2017, and we would like to sincerely thank all outgoing members for their invaluable time and effort, which has contributed to the journal.

Associate Editors:

Epileptic Disorders welcomes Guido Rubboli, Lieven Lagae, and Michalis Kourtroumanidis to join the team of Associate Editors:



Ingmar Blümcke
Erlangen, Germany



Michael Duchowny
Miami, USA



Aristea Galanopoulou
New York, USA



Alexander Hammers
London, UK



Yushi Inoue
Shizuoka, Japan



Philippe Kahane
Grenoble, France



Michalis Kourtroumanidis
London, UK



Doug Nordli
Los Angeles, USA



Lieven Lagae
Leuven, Belgium



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Dianalund, Denmark



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Torbjörn Tomson
Stockholm, Sweden



Sarah Wilson
Melbourne, Australia

EPILEPTIC DISORDERS (continued)

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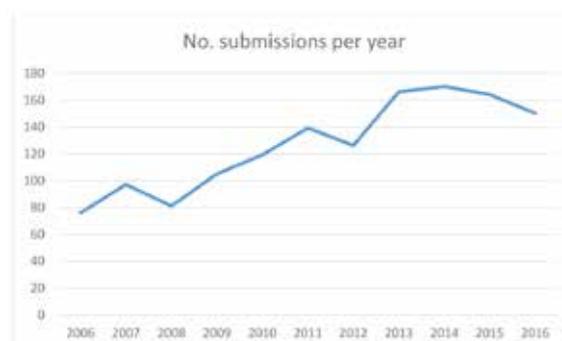
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Under the ILAE, *Epilepsia*, *Epilepsia Open*, and *Epileptic Disorders* are now more closely linked. All use the same ScholarOne submission platform. Editors-in-Chief of the three journals regularly collaborate within the Publications Task Force of the ILAE to better define the respective missions and target readerships.

Close collaboration between the Editors-in-Chief also permits, in accordance with the authors, consideration of the most appropriate journal, among the three journals, for the publication of a given manuscript.

For *Epileptic Disorders*, in 2016, of the manuscripts that were given a final decision, 39% were accepted and 61% rejected.



EPILEPTIC DISORDERS (continued)

Educational initiatives

Epileptic Disorders continues to publish *Original Articles* (42%), *Clinical Commentaries* (41%), review-style manuscripts (15%) (see below), and *Electroclinical Reasoning Reports* (2%) (percentages refer to 2016).

Review-style manuscripts

An important initiative of the journal over the last few years has been to develop review-style articles of high didactic value. At least two review-style manuscripts are generally included in each edition of the journal and regularly promoted via the ILAE and the *Epileptic Disorders* websites as Open Access papers. These include either *Reviews* (which discuss novel findings and state-of-the-art techniques, targeting an audience of specialists in epileptology), *Seminars in Epileptology* (relevant to general neurologists and child neurologists, focusing on general knowledge or everyday clinical practice and care), or *Learning from History*, a new series of article.

Learning from History articles encompass a wide range of different topics associated with the healthcare of epilepsy patients, covering either diagnostic or therapeutic issues, with an emphasis on *how* and *why* different concepts have changed over time or not. For example, the usefulness and perception of genetic screening or the evolution of treatment strategies (early vs late; mono vs. polytherapy) for a certain condition. These articles are expected to be of interest to adult and child neurologists.

Examples of published *Learning from History* articles include:

- Drug treatment strategies of epilepsy revisited. Starting early or late? One drug or several drugs?
Dieter Schmidt
- Dosing strategies for antiepileptic drugs: From a standard dose for all to individualised treatment by implementation of therapeutic drug monitoring.
Cecilie Johannessen Landmark, Svein I. Johannessen, Torbjörn Tomson

Most popular manuscripts accessed from the *Epileptic Disorders* website between 2013 and 2016.

Articles	Authors	Year	Vol/No.
Benign paroxysmal tonic upgaze of childhood with ataxia	Lispi and Vigevano	2002	Vol. 3 - N°4
Interactions between antiepileptic drugs, and between antiepileptic drugs and other drugs	Zaccara and Perucca	2014	Vol. 16 - N°4
Epilepsia partialis continua: Semiology and differential diagnoses	Bien and Elger	2008	Vol. 10 - N°1
Autonomic symptoms during epileptic seizures	Baumgartner, et al.	2001	Vol. 3 - N°3
Video atlas of lateralising and localising seizure phenomena	Stoyke, et al.	2011	Vol. 13 - N°2
A semiological classification of status epilepticus	Rona, et al.	2005	Vol. 7 - N°1
Visual phenomena and headache in occipital epilepsy: A review, a systematic study and differentiation from migraine	Panayiotopoulos	2000	Vol. 1 - N°4
Therapy of encephalopathy with status epilepticus during sleep (ESES/CSWS syndrome): An update	Veggiotti et al.	2012	Vol. 14 - N°1
Febrile seizures and genetic epilepsy with febrile seizures plus (GEFS+)	Camfield and Camfield	2015	Vol. 17 - N°2
The clinical pharmacology of traditional antiepileptic drugs	Vajda and Eadie	2014	Vol. 16 - N°4

EPILEPTIC DISORDERS *(continued)*

Epileptic auras: phenomenology and neurophysiology	Perven and So	2015	Vol. 17 - N°4
Frontal lobe epilepsy	Kellinghaus and Lüders	2004	Vol. 6 - N°4
Self-induced stretch syncope of adolescence: A video-EEG documentation	Mazucca and Thomas	2007	Vol. 9 - N°4
Non-convulsive status epilepticus: Epilepsy Research Foundation Workshop Reports	Walker, et al.	2005	Vol. 7 - N°3
Characteristic phasic evolution of convulsive seizure in PCDH19-related epilepsy	Ikeda, et al.	2016	Vol. 18 - N°1
Treatment of paediatric epilepsy: European expert opinion, 2007	Wheless, et al.	2007	Vol. 9 - N°4
Reflex operculoinsular seizures	Xiao, et al.	2016	Vol. 18 - N°1
Surgery for epilepsy: A systematic review of current evidence	West, et al.	2016	Vol. 18 - N°2
Concept of epilepsy surgery and presurgical evaluation	Rathore and Radhakrishnan	2015	Vol. 17 - N°1
Piracetam and levetiracetam: Close structural similarities but different pharmacological and clinical profiles	Genton and Van Vleymen	2000	Vol. 2 N°2

Epileptic Disorders website and education (www.epilepticdisorders.com)

With the launch of the new *Epileptic Disorders* website in 2014, as a fundamentally educational resource centre which is constantly being developed, the website is being increasingly visited, with now 294,179 visitors and 718,235 pages viewed in the last three years.

In the last year, the number of visitors increased by 5.85% and pages visited by 2%. The countries with the highest hits include: USA (27%), UK (7%), Italy (4%), France (4%), India (4%), Japan (4%), China (3%), Canada (3%), Spain (3%), and Germany (2%).

A focus is currently being made on providing a peer-reviewed library of educational images (with a short description) of neuroimaging, neuropathology, and EEG, as well as our video teaching library, which will also include surgical techniques.

EPILEPSIA OPEN

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New York, NY, USA



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Xuefeng Wang,
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Aims of *Epilepsia Open*

To publish through an open-access forum high-quality articles on all aspects of epilepsy research and clinical practice, including reviews, original research, opinions and commentaries, reports from regional and topic-specific ILAE commissions and task forces, brief communications and case reports. We aim to adhere to high-quality standards of reporting and publishing, as well as minimize publication bias, through the publication of not only studies with novel or positive findings but also negative, failure to confirm, or preliminary reports.

The stated mission of *Epilepsia Open* is "to make original epilepsy research on all aspects of epilepsy widely available through open access publication. More specifically, *Epilepsia Open* will fill a need in comprehensive epilepsy research by also including early, preliminary studies that may provide new directions for clinical and laboratory research as well as well-performed negative and failure to confirm studies."

Activities and Accomplishments

The Editors in Chief and Editorial Board, in collaboration with Wiley and the ILAE leadership when needed, have been convening via teleconferences or face-to-face meetings (Hoboken 2016, ECE Prague 2016, AES meeting Houston, TX) to discuss the progress, strategies, and action items, and advance the quality of the journal. As a result, there has been continuous improvement in the submission and journal website, author instructions, and content of the journal, as discussed in the following sections. There has also been frequent communication with the *Epilepsia* editors on papers that could potentially be transferred to *Epilepsia Open*.

Editorial Board: A prestigious multidisciplinary group of experts from all continents has been invited to the editorial board of *Epilepsia Open* (see above list)

EPILEPSIA OPEN (continued)

which encompasses experts of various countries and of diverse expertise, including clinical, basic science, or statistical expertise.

Marketing and increasing awareness of the journal: Wiley has built a marketing strategy that aims to build awareness of a new open-access journal for epilepsy research, to support uptake of referrals, attract direct submissions, and grow the journal's usage and reputation. This strategy includes branding of the journal and its URL, inclusion of information about the journal in the *Epilepsia* and Wiley websites, creation of banner stand at the European Congress of Epilepsy, creation of web banner ads for the first issue and the first ILAE report published in the *Epilepsia Open* (Scheffer et al, 2016), announcements in newsletters and press release for the journal launch and its first issue, ads in social media and print ads, and email newsletters and notifications for the new issues and accepted articles.

In parallel, the Editors in Chief have been flexible in providing waivers of the APCs when asked, so as to increase the awareness of the journal and facilitate submissions from authors who would have difficulty meeting the publication fee requirements.

As a result, there has been a steady increase in new visitors to the *Epilepsia Open* website from most continents (Europe, USA, Australia, and Asia mostly) and an increasing number of submissions to *Epilepsia Open*.

Published issues: Since its inaugural issue in September 2016, *Epilepsia Open* has already published three issues: September 2016 (Volume 1, issue 1-2), December 2016 (Volume 1, Issue 3-4), and March 2017 (Volume 1, Issue 1-2). These include 32 articles: three editorials and one commentary, five critical reviews, 13 full length and eight short original research articles, and two special reports from ILAE Task Forces.

Submissions: There has been an increasing and steady flow of submissions to *Epilepsia Open*. These are coming from two sources:

- (a) **Transfers from *Epilepsia*:** We currently receive as submissions to *Epilepsia Open* the 11.7% of the articles that we had offered transfer from *Epilepsia*. These comprise approximately 43% of the total submissions to *Epilepsia Open*. The acceptance rate is currently 72.4% and the rejection rate is 27.6%.
- (b) **Direct submissions to *Epilepsia Open*:** Direct submissions now comprise 57% of total submissions to *Epilepsia Open*. The acceptance rate is currently 78.8% and the rejection rate is 21.2%.

Overall, *Epilepsia Open* currently has a 24% reject rate and 76% acceptance rate, among articles with a final decision, following peer review. The majority of the articles are full-length original research (48%), or short research reports (25.3%), critical reviews or commentaries comprise 14% of articles, special reports 5% and the rest are editorials, invited original research, and hypothesis articles. The vast majority of the articles are clinical, including case reports (92.4%) and a small proportion are basic science (6.3%).

Currently, 40% (20/49) of the manuscripts that have been exported through to production have paid APCs. The countries of origin of these submissions with paid APCs are: Italy, Japan, US, Australia, The Netherlands, UK, Canada, Ireland, Finland, and India.

The Editors in Chief have also accommodated APC waivers to authors who have requested a waiver, in accordance with our decision to facilitate publications in our journal from authors who would have difficulty meeting the APC requirements. The countries of origin of these submissions include: Germany, Finland, The Netherlands, UK, Italy, Ireland, US, New Zealand, Kenya, Canada, Australia, and Uganda.

This steady and increasing flow of submitted manuscripts (from 4/month in March 2016 to 19/month in December 2016) has provided sufficient and increasing numbers of articles to ensure that our upcoming issue will have high-quality articles included.

Review times: Currently, the average time from submission to first decision is 27.9 days (including necessary author revisions prior to peer review sendoff), the average reviewer turnaround time is 11.2 days for original and 7.8 days for revisions, while the average time from submission to final decision is 56.7 days.

Application for the Directory of Open Access Journals (DOAJ): The application was submitted in December 2016 and a decision is anticipated in several months.

Recommendations for Future Work

Applications for inclusion to databases:
We plan to apply for the following databases:

- (1) **Application for PUBMED Central:** The number of already published articles at *Epilepsia Open* have exceeded the minimum required to apply for inclusion at Pubmed Central (i.e., 25 published articles). As a result, Wiley is currently preparing the application to PUBMED Central. This should be submitted by end of March or early April 2017.
- (2) **Application for EMBASE:** Application is planned to be sent after the June 2017 issue and by the October 1st deadline.

EPILEPSIA OPEN *(continued)*

- (3) **Application for PUBMED:** Eligibility for inclusion at PUBMED is expected to be around the middle of 2018, i.e., after two years of circulation of the journal. At that time, we anticipate that we will already have published the minimum of 40 articles required to apply.
- (4) **Application to other databases:** The planned timeline of submissions for inclusion to other databases is as follows: ESCI in August 2017, MEDLINE in February 2018, SCOPUS in February 2019.

Marketing: Further marketing campaigns are planned by promoting sample issues, promotions at conferences, journal app, and promotion upon inclusion to PUBMED Central. Promotions will be done via email, newsletters, online ads, press releases, print ads, social media, and surveys. We will also try to target with these marketing tools countries from all continents.

Submissions and workflow: Goals for the upcoming year are to:

- (1) increase the number of high-quality original research submissions,
- (2) increase the number of invited reviews and research from investigators and experts known for their high-quality publications on topics that are current and likely to generate interest from the readership,
- (3) accelerate the peer review time,
- (4) increase the number of basic science article submissions,
- (5) re-evaluate the needs and thematic priorities of our journal so that it becomes competitive in the field of epilepsy publications.

DIRECTOR OF INTERACTIVE MEDIA



Jean Gotman

HIGHLIGHTS

The ILAE website is a major window to the world, reflecting the diversity of the activities of ILAE. We believe the website should advance the ILAE's mission to "ensure that health professionals, patients and their care providers, governments, and the public world wide have the educational and research resources that are essential in understanding, diagnosing and treating persons with epilepsy." We have continued toward our goal of providing useful information about epilepsy to the diverse groups accessing the website. We primarily target three types of visitors: (i) those who know about ILAE and who come to the website searching for information related to ILAE activities (commissions, chapters); (ii) those who know about ILAE and come because they know that the website has information they need (congress information, guidelines); (iii) 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 largest one. It is a challenge, however, to present information to such diverse groups. Some of the highlights of the website and interactive media operations follow:

- We send a monthly e-Newsletter to our mailing list of members of the ILAE chapters who make this list available to ILAE (approximately 14,000 individuals). We also sent an e-Newsletter for exceptional announcements (e.g., elections of the ILAE president, publication of the new epilepsy classification, launch of *Epilepsia Open*)
- We hold monthly conference calls with representatives of Wiley and of the ILAE/IBE Congress Organization to coordinate the inclusion of important items in the different mailing lists of the three organizations (e.g. major congress deadlines, important articles).
- The different News sections of the ILAE website are updated frequently (on average once a week).
- In 2015 we restructured the website to facilitate access by graphically separating ILAE-related activities on the left side navigation of the homepage and general epilepsy-related activities in the top navigation line.

- The home page of the website is changed approximately once per month, to emphasize a major story related to ILAE or to the epilepsy world (major congress, election, release of an important document...).
- We have tried to collect information related to epilepsy in languages other than English from the ILAE chapters. We currently provide resources in 15 languages other than English (some sections have many documents, others have one or two).
- We have run a "Chapter Spotlight" feature on the homepage, where we presented during one month on the homepage information about the activities of 23 chapters who responded to our request.
- The three ILAE journals have a spot on the homepage and each provides information related to the latest activity of the journal. *Epilepsia* and *Epilepsia Open* are refreshed weekly, *Epileptic Disorders*, monthly.
- After each international or regional ILAE congress, we publish a report on the congress, including highlights and photographs. A system was setup such that the main congress organizer is asked ahead of time to prepare such a report in a relatively standard format.

The number of visits to the ILAE website has increased continuously in the last seven years, resulting in an almost 100% increase from 118,000 in 2010 to 234,000 in 2016 (Figure 1), and all other visitor metrics continue to be strong. Graphs and details about web activity are shown in Appendix 1.

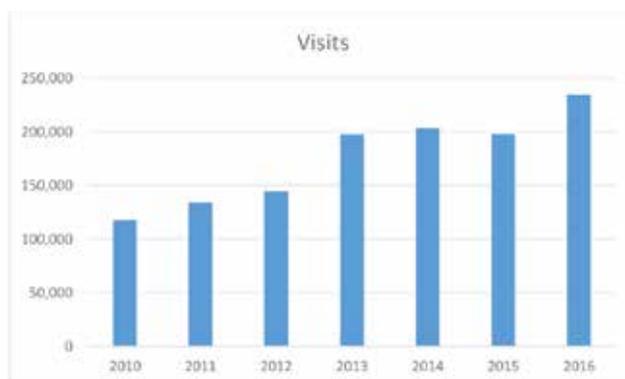


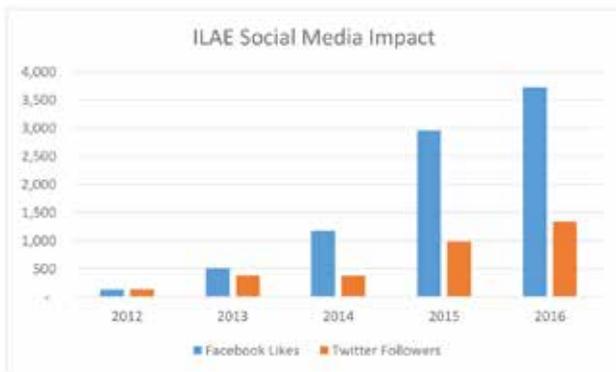
Figure 1

DIRECTOR OF INTERACTIVE MEDIA *(continued)*

SOCIAL MEDIA

A message is sent on social media (Facebook, Twitter) every time something is changed on the website (approximately five times per week). This means that a message is sent whenever we post a piece of news, congress information, a new guideline, an award, etc.

Our presence on social media has continued to increase with regular posts to Facebook and Twitter. During 2016, our Facebook “likes” increased 26%, to 3,733, and Twitter followers increased 36%, to 1,337. For the 2013 to 2016 term, our Facebook “likes” jumped 642% from 503 to 3,733, while our Twitter followers more than doubled, from 378 to 1,337 (254%).



WEB REDESIGN

In 2016, we embarked on a complete redesign of the website, with two major aims in mind:

1. Make the website responsive to the device from which it is accessed (computer, tablet or phone.) As phone access is rapidly increasing (now 21%; phone and tablet combined are 28.5%) it is imperative to present information adapted to the screen and interaction methods of the phone when the website is accessed from a phone, while maintaining the richness of presentation available on a computer screen. This is also important because Google has downgraded the ranking, in searches, of websites that do not change their format for mobile media.

2. Organize the content of the website in a Content Management System (a database for all the content of the website) to facilitate the display of information, its management and archiving. As an example of the power of such a system, we can display automatically on the congress page a vignette of whatever the latest piece of news from the homepage is (e.g. “new guideline on status epilepticus”). The many visitors who come directly to the congress page and do not see the homepage may thus be made aware of important news. The system can be set up such that this posting stays active for one month, for instance. Once set up, the system will remove outdated content autonomously.

This is a major project that will last approximately six months. We have identified partners for this task and have started discussing main design concepts. We expect completion in the Spring of 2017.

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. The daily supervision of activity is provided by Priscilla Shisler and Jean Gotman. This web team meets for a weekly conference call.

Submitted by
Jean Gotman, Priscilla Shisler, Deb Flower

OPERATIONS 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.



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.



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.



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 eNewsletter, Epigraph and the Annual Report.



As Lead Coordinator for the VIREPA program, Verena Hézszer-v. Wehrs worked closely with the Education Commission, course directors and tutors to administer, moderate and evaluate the successful VIREPA program. Verena retired in June 2016.



Finola Quinn administers and moderates the ILAE's successful VIREPA courses.

ILAE-IBE INTERNATIONAL DIRECTOR OF MEETINGS REPORT ON CONGRESSES



Richard Holmes

From July 2015 to June 2016, the Congress Team managed the 31st International Epilepsy Congress and the 11th Asian & Oceanian Epilepsy Congress. The International Director of Meetings Office also had a consultative role in the 3rd East Mediterranean & 5th UAE Joint Epilepsy Congress.

These congresses had a total of 3,836 attendees, 348 speakers and Chairs; 1,548 abstracts were received and 104 bursaries awarded.



31st International Epilepsy Congress, Istanbul, Turkey

5th-9th September 2015

The organising committee, chaired by Athanasios Covanis (Greece) and Emilio Perucca (Italy), comprised 10 members. The venue was the International Convention & Exhibition Centre ICEC. There were 2,550 attendees and 106 countries were represented.

Conference program:

- The programme comprised 85 sessions, with 220 speakers and Chairs.
- The programme was created by the Scientific and Organising Committee incorporating proposals submitted by ILAE and IBE Chapters and commissions/committees. Main session topics: 'Epilepsy imaging: Not only a focus, not only a network'; 'Epilepsies related to the immune system'; 'Classifying seizures and epilepsy: Where are we going?'; 'Comprehensive approach to patients of all ages with new onset seizures'; 'Advances in the treatment of Status Epilepticus'.
- The Presidential Symposium: "Doctor, is my epilepsy genetic and what consequence does it have?"
- The scientific programme had a wide range of main and parallel sessions, teaching sessions, debates, multidisciplinary conferences and video sessions, and ended with highlights session and a fun learning quiz.
- 95 abstracts were selected for platform presentation in 19 sessions.
- A stimulating education programme was created by the Education Committee, coordinated by Walter van Emde Boas (The Netherlands).

Other highlights:

- Awards presented:
 - Lifetime Achievement Award – Frederick Andermann (Canada)
 - Social Accomplishment Award – Shunglon Lai (Taiwan, Republic of China)
 - Ambassador for Epilepsy Awards – Ed Bertram (USA), Ingmar Blümcke (Germany), Roberto Caraballo (Argentina), Denise Chapman (Australia), Aristeia Galanopoulou (USA), Jean Gotman (Canada), Mike Kerr (United Kingdom), Philippe Ryvlin (Switzerland), Dennis Spencer (USA), Frank Vajda (Australia), Steve White (USA), Elza Marcia Yacubian (Brazil)
 - The Michael Prize – Jeanne Paz (USA)
 - Epilepsia Prize – Matthew Diamond (USA)
 - Epileptic Disorders Educational Prize – Alexandra Liava (Italy)
 - Harinarayan Young Neuroscientist Award – Cristina Ruedell Reschke (Ireland) & Ping Zheng (Australia)
- There were two special displays – the "Epilepsy and Me" painting contest organised by the Turkish Epilepsy Society for children and adolescents with epilepsy and the "Be Objective to Epilepsy" photography contest organised by the Turkish Epilepsy Society.
- 1168 abstracts were received and 74 bursaries were awarded.



3rd East Mediterranean & 5th UAE Joint Epilepsy Congress, Dubai, UAE

3rd-5th March 2016

This congress was hosted jointly by the International League Against Epilepsy, the International Bureau for Epilepsy and the Emirati League Against Epilepsy. The Congress Committee was chaired by Taoufik Alsaadi (UAE), Hassan Hosny (Egypt) and Najib Kissani (Morocco) and comprised of 10 members. The venue was the Intercontinental Hotel, Festival City, Dubai. There were 224 attendees and 28 countries were represented.

INTERNATIONAL DIRECTOR OF MEETINGS *(continued)*

Congress programme:

- The programme comprised 17 sessions, with 25 speakers.
- The programme covered an extensive range of topics with plenary, video and debate sessions on 'Practical issues'; 'Epilepsy across all ages'; 'Epilepsy comorbidities'; 'Epilepsy surgery'; 'Social issues in CEMA region'; 'Controversies in epilepsy'; 'Hot topics in epilepsy'.
- The Keynote Talk was 'Botanicals and epilepsy'.
- An EEG Course and a Multiple Sclerosis Symposium took place on the first day.

Other highlights:

- 27 oral communications and posters were presented.



11th Asian & Oceanian Epilepsy Congress, Hong Kong

7th-10th May 2016

The Scientific Organising Committee was chaired by Denise Chapman (Australia), Byung-In Lee (Korea) and Ada Yung (Hong Kong) and comprised of 10 regional members. The venue was the Hong Kong Convention and Exhibition Centre (HKCEC) situated right in the centre of Hong Kong. There were 1,062 attendees and 51 countries were represented.

Congress programme:

- The programme comprised 49 sessions, with 103 speakers and Chairs.
- The programme covered an extensive range of topics selected from recommendations submitted by Asian and Oceanian ILAE and IBE Chapters. Main session topics: The Chairman's Symposium: 'Autoimmune encephalitis'; 'Epilepsy and behaviour'; 'New paradigms of AED therapy'; 'Genetics in epilepsy'.
- The Masakazu Seino Memorial Lecture: 'Exploring the mysteries of EEG'.
- The main sessions were complimented by a comprehensive mix of post main and parallel sessions, didactic lectures, video quizzes, debates, forums, workshops and teaching courses. As a new feature to the programme, the main task forces of the CAO each organised a session.

- The day-long Epilepsy & Society Symposium covered topics ranging from the naming of epilepsy in the region and beyond, to technology advances in the diagnosis of epilepsy, and enhancing medical and nursery care, as well as heartfelt sharing from people with epilepsy and caregivers. The day was rounded off with an excellent puppet performance on living with epilepsy put on by a local children's group famous worldwide.

Other highlights:

- Awards presented:
 - Asian Oceanian Outstanding Achievement Epilepsy Awards (ILAE) – Yuang gui Huang (China), Patrick Kwan (Australia), KV Muralidharan (India), Manjari Tripathi (India)
 - Golden Light Awards (IBE) – M Amarjargal (Mongolia), Amrita Bhashyam (India), Rosalind Chee (Malaysia), Jeong Ja Jee (South Korea), Yin Chan Loke (Singapore), Kim Meers (Australia), Wai Hung Ng (Hong Kong), Kun Hoo Rhee (Nepal), Zhi-Gang Wang (China), Laura Liu Yi (Taiwan, Republic of China)
 - Tadokoro Awards: 1st Prize, Platform – See He Kim (South Korea); 2nd Prize, Platform – Kheng-Seang Lim (Malaysia); 1st Prize, Poster – Rajesh Kumar Goit (Nepal); 2nd Prize, Poster – Aijie Liu (China)

Future Congresses

The **9th Latin American Congress on Epilepsy**, Cancun, Mexico and the **12th European Congress on Epileptology**, Prague, Czech Republic took place in August and September 2016 respectively, and will be included in the Annual Report for July 2016-June 2017.

The Congress Team is currently working on arrangements for the upcoming congresses in 2017 (**4th East Mediterranean Epilepsy Congress**, Luxor, Egypt; **3rd African Epilepsy Congress**, Dakar, Senegal; 32nd International Epilepsy Congresses, Barcelona, Spain) and 2018 (**10th Latin American Congress on Epilepsy**, San Jose, Costa Rica; **12th Asian & Oceanian Epilepsy Congress**, Bali, Indonesia; **14th European Congress on Epileptology**, Vienna, Austria), as well as the IEC in 2019 and regional congresses in 2020.

Richard Holmes
International Director of Meetings



Task Force Reports 2013 – 2017

EPILEPSY EDUCATION TASK FORCE



Sam Wiebe

Chair

Sam Wiebe (Canada)

Members

Emilio Perucca (Italy)
Taoufik Al Saadi (UAE)
Alexis Arzimanoglou (France)
Ingmar Blumcke (Germany)
Patricia Braga (Uruguay)
Jaime Carrizosa (Colombia)
Stefan Hermann (Germany)
Jaideep Kapur (USA)
Pierre Luabeya (DR Congo)
Gary Mathern (USA)
Astrid Nehlig (France)
Benickzy Sándor (Denmark)
CT Tan (Malaysia)
Nigel Tan (Singapore)
Tomson Torbjorn (Sweden)
Sarah Wilson (Australia)

Staff liaisons

Priscilla Shisler (USA)
Verena Hézser-v.Wehrs (Germany) Retired

The educational offerings of the ILAE are vast and are truly global in nature. These opportunities are supported financially by the ILAE and developed by regional and topical commissions and task forces. There are also many educational activities developed under the auspices of ILAE national chapters as well as other organizations working in the epilepsy community. All of these options vary greatly in content, instructional design and format, target audience and cost. The Epilepsy Education Task Force, which has representation from all regions, was formed to develop a comprehensive education framework that achieves the ILAE's mission at as low a cost as possible, addresses opportunities and needs and is globally applicable. This encompasses understanding educational needs of the varied global audience involved in the diagnosis and treatment of epilepsy, maximizing use of existing resources, exploring new ideas, and looking at what is working in one region that can be utilized in another. The focus is broad, including both live and online activities, regional and international.

The Task Force began its work by looking strategically at the goal of developing a global education framework through a PESTO analysis (Political, Economic, Socio-cultural and Technological factors) to

think about external factors that could impact, positively or negatively, our educational mission, and a SWOT analysis (Strengths, Weaknesses, Opportunities and Threats) of League-supported online activities and resources, published materials, and live educational activities, to consider what we think we do well, what needs improvement, and what new areas or trends are there to contemplate.

The Task Force identified that the strengths of the League's educational opportunities include the fact that there is a variety of offerings at the ILAE congresses (therapeutics sessions, case-oriented teaching sessions, "how to" sessions), there are excellent online learning opportunities through the VIREPA (Virtual Epilepsy Academy) courses and the Diagnostic Manual, www.epilepsydiagnosis.org, and there are excellent resources in terms of published materials, such as the ILAE's journals (Epilepsia, Epilepsia Open, Epileptic Disorders), and commission and task force reports. Additionally, the ILAE is seen as the authority in the field of epilepsy, and of course there is the huge resource of the many committed individuals who dedicate their time and expertise to the League's work. There was consensus that the ILAE should be developing the body of knowledge for epilepsy diagnosis and treatment. The challenge is how to effectively organize and disseminate information about the educational resources of the ILAE to a world wide audience at as low a cost as possible.

Other activities under way:

- To develop a system to evaluate the effectiveness of the League's educational activities, a post-activity evaluation instrument was created for use by all League-supported activities.
- Create new online education options which are less resource-intensive and can educate more people at a lower cost, while continuing to support and improve upon the highly successful VIREPA courses.

As discussed in the Education Commission report, a successful online, language and cost-friendly education program was designed and implemented in Latin America by the Education Commission under the leadership of Drs Jaime Carrizosa and Patricia Braga. This program provides a certificate to successful students. The aim is to decrease the diagnostic and therapeutic gap in epilepsy for primary care providers and is likely to be implemented in other settings.

EPILEPSY EDUCATION TASK FORCE *(continued)*

Explore an online imaging platform to be used in distance learning activities. This is well underway and near implementation.

Explore an online-only, web-based EEG platform for distance learning. This is in its early stages of exploration.

- Collaborate with Wikipedia, which provides an incredible opportunity for unparalleled penetrance of information about epilepsy in many languages, to improve and increase quality content for epilepsy.

A Chief Editor, Dr Günter Krämer, and Editorial Board, Associate Editors Drs Selim Benbadis and Nicola Maggio, have been identified and are moving this project forward. Their work will include revising current Wikipedia epilepsy content, adding new content and creating new articles that are publication ready.

As part of this project, the ILAE website now contains the Creative Commons Attribution-ShareAlike copyright license, allowing anyone to utilize and share material on our website as long as it is attributed appropriately.

- Create a digital portal to organize epilepsy education materials and resources in a central area.

This education portal, or virtual epilepsy campus, will be done as part of the launch of the newly redesigned ILAE website.

- Revamp our live education to allow for more interactivity by combining didactic lectures with more opportunities for interactive, case-based sessions.

- Develop an epilepsy curriculum framework to allow for the organization of educational resources in order to provide an asset map of what is available world-wide to epileptologists, neurologists and other health care providers for persons with epilepsy, and also to determine educational gaps. The curriculum will be based on a set of key competencies that epileptologists should have to effectively meet the needs of their patients with epilepsy.

As a first step, and with the assistance of consultant Dr. Lara Cooke, Dean of the Office of CME and Professional Development, University of Calgary, and a neurologist, the Task Force agreed upon, refined and categorized core competencies for epileptologists.

Feedback on the competencies was sought from the epilepsy community through a survey. The response to the survey was good (over 700 responses), providing general agreement on the core competencies drafted.

From the competencies, Dr. Cooke developed detailed learning objectives for each competency

Still to be done is to map the objectives against existing educational opportunities, identify the educational gaps, and propose methods and formats to address these gaps, and to develop educational design guidelines for the development of new materials

- Explore a credentialing program for epilepsy specialists. The responses to the aforementioned survey confirmed broad interest in, and support for, having some sort of credentialing process.

EPILEPSY GUIDELINES TASK FORCE



Nathalie Jetté

Chair

Nathalie Jetté (Canada)

Members

Africa

Jo Wilmshurst (South Africa)

Asia

Nobukazu Nakasato (Japan)

Yuping Wang (China)

Sanjeev Thomas (India)

Europe

Colin Dunkley (UK)

Eva Kumlien (Sweden)

Jozsef Janzky (Hungary)

Emilio Perucca (Italy)

Latin America

Horacio Senties (Mexico)

North America

Nathalie Jette (Chair) (Canada)

Solomon Moshe (USA)

Timothy Pedley (Chair) (USA)

Khara Sauro (Canada) - PhD student

Samuel Wiebe (Canada)

Clinical Practice Guidelines Process

Working Group

Europe

Colin Dunkley (UK)

Emilio Perucca (Italy)

Latin America

Alejandro deMarinis (Colombia)

North America

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

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

This group had several conference calls and a face-to-face meeting (December 2006, Houston, USA) to discuss ongoing tasks of this group.

Main activities have included:

- An update of the systematic review of epilepsy guidelines. Approximately 1,405 abstracts were reviewed, 54 full text articles and four new guidelines were identified.
- Creation of a podcast on guideline development.
- Development of a protocol to test the new ILAE guideline process manual in a low and high income region. External funding will be required (a grant application is ready for submission)
- The creation of a list of attributes that will be used to classify all of the identified evidence-based epilepsy guidelines on the ILAE website so that users can easily access all of these resources to facilitate evidence-based care
- Preparation of an elaboration paper (educational paper regarding guidelines) is underway that will address:
 - What is and what is NOT a guideline
 - Why so many "guidelines" are NOT guidelines (will include data of # of guidelines excluded in prior systematic review on guidelines attached and how many were from high vs. low impact journals, etc.)
 - Why it is important to do a systematic review when preparing a guideline
 - Why it is important to grade the level of evidence and strength of the recommendations in a guideline

EPILEPSY GUIDELINES TASK FORCE *(continued)*

- What to do when the evidence is poor (e.g. consensus methodology, etc.)
- What should people do with non-guideline publications (consensus, opinion, etc), i.e., they still have a role, but have a lower ranking in evidence-based medicine. Increasingly people should use systematic approaches for consensus-based statements.
- What to do about applicability of guidelines
- When should overarching vs region/culture specific guidelines should be developed
- Future directions (e.g. there should be standards of reporting for guidelines as there are for other types of publications)

Recommendations for Future Work

The group will continue to update the systematic review of epilepsy guidelines annually. A subgroup will be created to review the state of guidelines and standards regarding driving in epilepsy internationally so that global recommendations can be made to drive policy regarding driving in epilepsy. A new working group will also be created and will develop guidance on guideline implementation strategies and how to adapt existing guidelines in low-and middle-income countries. Work on developing a new strategic plan that highlights long-term goals and scope for the ILAE Epilepsy Guidelines Task Force.

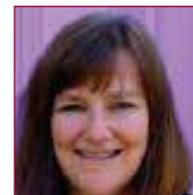
Report by:

Nathalie Jetté and Khara Sauro

GLOBAL OUTREACH TASK FORCE



Alla Guekht



Mary Secco

Chair

Alla Guekht, Russia (on behalf of the ILAE)

Mary Secco, Canada (on behalf of the IBE)

End of Term Report (2013 – 2017)

1. WHO and the Epilepsy Resolution

It was the strategic activity of the GOTF. We wish to acknowledge the dedicated members of current and past executives, chapters and associations who have worked tirelessly to improve the lives of people with epilepsy through their involvement with the ILAE, IBE and the WHO. The joint efforts of thousands of people all over the world, coordinated by the ILAE and IBE Presidents, Emilio Perucca and Thanos Covanis, were highly successful. Collectively, their voice was recognized on May 26th, 2015 with the passing of an epilepsy resolution at the 68th World Health Assembly.

In the fall of 2014, the People's Republic of China made a formal request to the World Health Organization (WHO) to have epilepsy included in the agenda of the 136th WHO Executive Board meeting. We would like to acknowledge the outstanding contribution of Dr. Shichuo Li, the Past-Chair of the GOTF in making it possible. The draft of the Resolution calling for a Global action plan to be implemented under the umbrella of the WHO and in partnership with ILAE and IBE was prepared.

The concept of the Resolution and the Global action Plan was presented to the Minister of Health of the Russian Federation, Professor Veronika Skvortsova, and the first country to take an active step in co-sponsoring of the Resolution was the Russian Federation, which liaised with the Chinese delegation in advancing the draft of the Resolution. Another co-sponsor that came in at a later stage was the Maldives.

The agenda item on epilepsy and the draft Resolution were discussed at the 136th WHO Executive Board meeting on February 2, 2015. The support was overwhelming, with 28 countries, some speaking on behalf of other nations from the same region, standing up and making positive statements about the Resolution. Valuable suggestions to refine the text came from several countries, and eventually the Executive Board voted unanimously to submit the Resolution to the 68th World Health Assembly. In addition to the People's Republic of China, the Russian Federation, and the Maldives, four other countries (Argentina, the Islamic Republic of Iran, Japan, and Panama) requested to co-sponsor the resolution at the Board meeting. Members of the GOTF were in

attendance at the Executive Board meeting and were able to liaise with delegates to promote the draft. They joined member states in refining the wording of the Resolution.

During the months that followed, there was overwhelming enthusiasm and intensive mobilization of ILAE and IBE chapters around the globe. The role of the GOTF was to join others in providing guidance to ILAE and IBE chapters. It was also to provide chapters with the tools to meet with their national policy advisors and health ministry officials to reinforce the need to treat epilepsy as a major health priority. On April, 8, there was a meeting of the ILAE and IBE leadership with the Minister of Health of the Russian Federation Professor Veronica Skvortsova, where some issues of the strategic collaboration and support of the Resolution were discussed (photo below); the meeting with the Vice-Minister of Kazakhstan followed.



Members of the GOTF had the privilege of attending the WHO Executive Board and the 68th World Health Assembly where they met with member states to answer questions about specific details of the Resolution and to encourage delegates to co-sponsor or vote in favor of the Resolution. On Tuesday, May 26, 2015, the World Health Assembly approved unanimously Resolution WHA68 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." A total of 42 countries from five continents made official statements and 19 countries acted as co-sponsors. [See Commentary: The World Health Assembly's Resolution on Epilepsy.](#)

The Epilepsy Resolution provides the ILAE/IBE members with a powerful tool to engage governments into taking concrete action to improve epilepsy care, promote public awareness and allocate resources to epilepsy resources. The GOTF continues to work with the WHO to discuss opportunities to implement the key recommendations in the Epilepsy Resolution:

GLOBAL OUTREACH TASK FORCE *(continued)*

- GOTF members contributed to the sessions and materials on the WHA Resolution that were presented at the 31st IEC in Istanbul.
- A tool kit developed by the WHO and situation analysis templates have been distributed to IBE chapters.
- The WHO partnered with the GOTF to promote International Epilepsy Day. Photos and information about epilepsy were featured on the WHO website and materials were distributed through the WHO health networks.
- GOTF contributed to the preparation of the World Brain Day 2015, dedicated to Epilepsy - the initiative of the WFN, to which WHO, ILAE and IBE were invited to participate.
- The meeting on “Brain diseases – Medical and social aspects” was performed in collaboration with IBE, Russian MoH, World Federation of Neurology, European Academy of Neurology, World Stroke Organization, Moscow Research and Clinical Center for Neuropsychiatry and others; Head of the WHO Special Representative Office in the Russian Federation attended the meeting.
- The Post-Resolution meeting during the World Congress of Neurology in Chile with participation of WHO representative (Tarun Dua) (WHO), ILAE Treasurer (Sam Wiebe) was arranged in collaboration with the Commission on Latin American Affairs and Task Force for the Strategic Plan for Latin America; the perspectives of developing the region-specific initiative were presented. It was mentioned that Latin American countries could be the model areas for Troina (Improving Access to AEDs) project.
- The Post-resolution meeting during the 12th ECE in Prague with the WHO representative (Tarun Dua) and ILAE/IBE Presidents and EC members was organized; the collaboration between the WHO, ILAE and IBE in preparation of the Epilepsy report (to be presented at the 71th WHA) was discussed; in terms of the implementation of the WHA Resolution – it was agreed to identify three countries to become regional models for collaboration (Eastern Europe, Latin America, Middle East).
- A meeting with the WHO Assistant DG Dr. Oleg Chestnov took place with the discussion on epilepsy as one of the key NCD comorbidities.
- The meeting of the GOTF took place in Istanbul, during the 31st IEC; delegates from Latin America, Asia and Africa brainstormed on implementation of

the Resolution in these regions.

- The work on the Global Epilepsy Report is ongoing (in collaboration with ILAE/IBE leadership and other Task Forces).

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

Given the importance of access to antiepileptic medicines, the workshop brought together key stakeholders from the WHO, ILAE, IBE, Health Action International and representatives from Ministries of Health to discuss opportunities for achieving long-term affordable access to essential medicines for epilepsy. It was stated that treatment gap is the multifaceted domain, influenced by the diagnostic and therapeutic deficits, including lack of personnel (manpower gap), limited AEDs supply, poor adherence to medication, economic conditions, cultural beliefs and many other factors; the need to better define and investigate the treatment gap was appreciated. A number of demands, especially important for the LAMIC countries, were acknowledged, including the role of non-specialist health care providers and the impact of ignorance and stigma.

3. Collaboration with the WFN and other organizations in Neurology

As already outlined, the collaboration with the WFN (World Federation of Neurology) was strengthened during this term that led to WFN support of the Resolution of epilepsy and dedication of the World Brain Day 2015 to promoting a common action against epilepsy. The WFN invited WHO, ILAE and IBE to participate in World Brain Day activities strengthening collaboration and raising awareness about epilepsy to neurologic societies around the globe.

The productive collaboration between the ILAE and the WFN has been emphasized at the Council of Delegates of the WFN during the 12th European Congress on Epileptology in Prague and in the [November 2016 issue of World Neurology](#).

The meeting and course on brain diseases was performed in collaboration with IBE, Russian MoH, World Federation of Neurology, European Academy of Neurology, World Stroke Organization, and participation of the Head of the WHO Special Representative Office in the Russian Federation in April 2016. Implementation of the WHA Resolution

GLOBAL OUTREACH TASK FORCE *(continued)*

on Epilepsy has been discussed with Professor V. Skvortsova, the Russian Minister of Health, one of the co-sponsors of the Resolution. Epilepsy was discussed as one of the NCDs (non-communicable diseases) and the comorbidity of the other major NCDs – stroke, dementia and others. The collaborative strategies focused on improvement of epilepsy care in line with the prevention and care of other NCDs, was one of the central topics of the meeting. There were 686 participants, including leading healthcare authorities from Russia (48 regions), Belorussia, Kazakhstan, Uzbekistan.

The meeting with the ILAE leadership with the Board members of the World Stroke Organisation took place in October 2014; collaboration in terms of the NCDs was discussed.

GOTF members represented ILAE at the World Brain Alliance meeting (alliance of international neurological organizations acting worldwide to ameliorate the burden of brain and mental diseases) during the EFNS/ENS Congress in Istanbul in 2014 and the Global Neurology Network meeting at the EAN Congress in 2016.

4. Young Adult Summit

A group of 20 young adults representing the United States, Canada, Puerto Rico and Jamaica gathered in Washington, DC to participate in the ‘Young Adult Epilepsy Summit’ organized by the International Bureau for Epilepsy. The event comprised of a weekend filled with workshops and discussions to talk about the core issues of those affected by epilepsy. As a result of the summit, the Twenty-20s group was tasked with developing an initiative that would raise awareness about epilepsy through the sharing of their personal stories.

In October 2015, members of the group met in Toronto, Canada to film their personal videos. Using social media, the young adults have shared their stories worldwide. They have developed a governance structure and continue to meet monthly via teleconference. This group of epilepsy champions has established a Facebook page and continue to track the growth of their online audience. They are committed to working with young adults in all regions to reduce the burden of epilepsy on the individual, their families and their community.

5. Eastern European collaboration (including activities aimed on identification of one of the “model” regions for implementation of the Resolution).

In the framework of implementation of the WHA Resolution, several projects are being performed (in collaboration with the local health authorities) in the countries of the region in order to accumulate data on epidemiology and social issues of epilepsy (including treatment gap and attitude towards PWE) and to identify appropriate interventions. (These projects are being done in collaboration with Prof. W. A. Hauser and Prof. D.Hesdorffer).

The study on attitudes to PWE in Moscow has been completed and published. Further investigation on stigma and the strategies to ameliorate it is ongoing. In 2016-2017, there were several meetings with the healthcare authorities and Chapter leaders of Georgia and Byelorussia on the implementation of the Resolution (in Moscow, Minsk and Tbilisi).

The projects in Kazakhstan seem to be the most successful. The study on prevalence and treatment gap in South Kazakhstan has been completed and published. There was an intensive collaboration with the local authorities with several interventions aimed at improvement of care and education initiatives (including the meeting with the ILAE /IBE leadership in Almaty in November 2013 and the course in Astana in 2015– please see below).

The meeting with leading specialists and healthcare authorities from Kazakhstan, Uzbekistan and Tajikistan took place in Moscow in April 2017. The positive impact of the project in Kazakhstan has been underlined with the significant decrease of the treatment gap (data to be further analyzed, and then presented and published). Further development of the project, including the study on attitudes to PWE in South Kazakhstan, had been elaborated with the realistic possibility to make South Kazakhstan one of the “model regions” in implementation of the Resolution (to be confirmed with the healthcare authorities at the country level).

Several other important activities during this term (in collaboration with the Commission of European affairs) were targeted to the European (geographically Asian) countries of the former Soviet Union – the area of huge unmet needs in improvement of care for PWE and education in epilepsy. There are five countries in the region (Kazakhstan, Uzbekistan, Kyrgyzstan,

GLOBAL OUTREACH TASK FORCE *(continued)*

Turkmenistan, Tajikistan), with three existing ILAE Chapters (Kazakhstan, Uzbekistan, Kyrgyzstan). The collaboration with doctors from Turkmenistan and Tajikistan is ongoing with the potential formation of the Chapters. In 2015, the meeting and regional course in Astana (Kazakhstan) took place. It was highly successful, with more than 250 participants from Kazakhstan, Uzbekistan, Kyrgyzstan and other countries in the region. The very productive meeting of the ILAE/IBE leadership with the Vice-Minister of Health and other top healthcare authorities took place.

The work of the Global Outreach Task Force was focused on the Resolution-related initiatives, the improvement of the visibility of epilepsy at the WHO, promotion of the activities of the epilepsy-related projects on the global and regional level, strengthening of the healthcare systems for epilepsy, combatting the treatment gap, and stigma and discrimination of PWE. We intend to increase partnerships and collaboration with other organizations for the benefit of the epilepsy education and care for PWE.

PUBLICATIONS TASK FORCE



Torbjörn Tomson

Chair

Torbjörn Tomson (Sweden)

Members

Alexis Arzimanoglou (France)

Edward H. Bertram, III (USA)

Aristea Galanopoulou (USA)

Jean Gotman (Canada)

Gary Mathern (USA)

Astrid Nehlig (France)

Emilio Perucca, EC Liaison (Italy)

Dieter Schmidt (Germany)

Michael Sperling (USA)

Xuefeng Wang (China)

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; more specifically ILAE's official journals- *Epilepsia*, *Epilepsia Open*, and *Epileptic Disorders*.

Commission Activities

June 2014 through June 2015

The Task Force has had 1-3 face-to-face meetings each year.

Accomplishments (2014-2015)

The current term has been a very dynamic period with regard to ILAE publications. The League acquired *Epileptic Disorders* as its Educational Journal, and also launched *Epilepsia Open* as the open access alternative. It has been the aim of the Publication Task Force to advise the ILAE Executive and to assist in this development.

A major task has been to develop and clarify the distinct roles of the three journals in order to guide potential authors as well as the readership. In this process, each journal has fine-tuned its profile describing its Mission, target readership, target authorship, types of articles, and special features. These statements are posted on the ILAE website. Another way of expressing the journals' specific roles and directions has been to establish awards for best

articles. Hence *Epilepsia* now offers one annual prize for best publication in clinical research and one for best publication in basic science. *Epileptic Disorders* awards the best educational publication in the journal.

An important role of the Publication Task Force has been to serve as a forum for discussion of matters of mutual interest amongst the Editors of the three ILAE journals. As one example, in particular with the launch of *Epilepsia Open*, it became important to establish an agreement of procedures for smooth transfer of manuscripts between the ILAE journals if a paper was considered to be more in line with the scope of another of the League's journals than the one it was originally submitted to. This is now in place to the benefit of authors as well as the journals.

The Publication Task Force has been involved in the management of reports from other commissions and task forces. A document describing the principles and procedures for publication of commission/task force reports has been developed and circulated to all relevant commission/task force chairs. In accordance with these rules, the Publication Task Force now screens all commission/task force reports (except ILAE Position Papers) for concept and provides recommendations to the ILAE Executive regarding suitability for publication and to which of the ILAE journals.

Recommendations for Future Work

Continue to monitor the development of the three journals and their profiles. Be part of the development of ILAE involvement in Wikipedia. Contribute to the development of the overall ILAE publications strategy, including utilization of new media for publication.

GLOBAL RESEARCH PRIORITIES AND ADVOCACY TASK FORCE

Co-Chair

Helen Cross, Philippe Ryvlin, Shichuo Li

Members

Dan Lowenstein (USA)
Pierre (Mesu'a-Kabwa)
Luabeya (Congo)
Fernando Cendes (Brazil)
Gay Mitchell (MEP)
Ding Ding (China)
Terence O'Brien (Australia)
Ray Dingleline (USA)
Makiko Osawa (Japan)
Alla Guekht (Russia)
Mary Secco (Canada)
Dale Hesdorffer (USA)
Andy Shih (USA)
Akio Ikeda (Japan)
Jo Wilmshurst (South Africa)
Merab Kokaia (Sweden)
Thanos Covanis (IBE, Greece)
Patrick Kwan (Australia)
Emilio Perucca (ILAE, Italy)

Aims

The ILAE Task Force for Global Research Priorities was formed in September 2014. Although there had been several initiatives both at a regional and topic level to define research priorities in epilepsy, it was clear that benefit and leverage for advocacy could be gained if these were reviewed on a more global scale, as well as to open up funding opportunities for epilepsy research on a global scale. Individuals with regional representation were asked to join, chaired by P Ryvlin and JH Cross, and an initial meeting was held in December 2014.

At this time, the methodology as to how we may go about this was discussed. A project plan was developed as to how research priorities may be determined. In the first instance, the community was surveyed through direct questions to Commissions and Task Forces about what they defined as the 4-5 major gaps in epilepsy research in their areas. We then realized that two sets of priorities were emerging; firstly those questions that needed to be addressed on a global scale, and a second set that could be addressed at a local level but would have global applicability.



Helen Cross



Philippe Ryvlin



Shichuo Li

An ILAE/ IBE Task Force for Global Research Advocacy was formed at the outset of the term, chaired by Shichuo Li. This had already reached significant achievements. Firstly, on behalf of the IBE, they made a statement on the 65th WHO Western Pacific Regional Committee meeting (65th RCM) in Manila, Philippines, to promote epilepsy in the western Pacific region and, secondly, worked at the 136th Executive Board meeting of the 68th World Health Assembly of the WHO in 2015 resulting in the WHA 68.20 resolution on epilepsy being passed. It was realized at this stage however that the two Task Forces would achieve more if working together, so the two were merged to form the ILAE/IBE Task Force for Global Research Priorities and Advocacy.

Next steps were to post the research questions on the web for prioritization by the community. We achieved 204 responses, from all continents of the world. This has resulted in five top priorities in each category; a publication for reporting on these priorities is currently in preparation.

In parallel, we recognized that formulating such priorities could give progress to addressing the possibility of a global project funded by multiple agencies from around the world. Despite a number of major research calls funded by NIH and the EU during the last decade, financial support for epilepsy research lags behind most comparably prevalent or severe neurological and non-neurological disorders. Accordingly, no significant progress has been made in reducing i) the incidence or prevalence of epilepsy, ii) the proportion of patients whose seizures remain treatment-resistant, and iii) the death toll resulting from the disease. Working with the American Epilepsy Society, preliminary meetings and teleconferences were organized separately with the neuroscience section's director at DG research (the EU agency in charge of the H2020 EU research framework program), and with the director of the epilepsy program at NIH/NINDS. Following encouraging feedback from these agencies, it was decided to prepare a more detailed draft of potential projects identified by the community that could be considered for a multinational collaborative research effort. Such an initiative would also address the priorities identified by the 2015 resolution of the World Health Assembly on epilepsy. Following discussion, it was decided that the following priorities should be considered for further funding:

GLOBAL RESEARCH PRIORITIES AND ADVOCACY TASK FORCE *(continued)*

- 1) To establish the feasibility of primary and secondary prevention of epilepsy in patients with stroke and/or traumatic brain injury (TBI).
- 2) To establish the effectiveness of extra-temporal lobe surgery in populations stratified by etiology, pre-surgical algorithm, site of the epileptogenic zone and surgical approach.
- 3) To establish the effectiveness of interventions aimed at reducing the risk of SUDEP.
- 4) To develop and establish an effective mobile health program tackling critical issues for people with epilepsy worldwide, including knowledge about epilepsy and epilepsy care, anti-epileptic treatments, co-morbidities, and social issues.
- 5) To determine through the enrolment of a large cohort the phenotype variability to the epilepsies, with the objective of personalizing therapies for seizures, syndromes and related comorbidities.

After discussion, it was determined that the two priorities that fell in line with global initiatives were evaluating epilepsy following TBI, and the topic of SUDEP. Further to a discussion with NIH/NINDS, in February 2017 a joint workshop was held at the European Union, Brussels, hosted by Brian Hayes, Chair of the MEP Advocacy Group for Epilepsy, with participation from ILAE, IBE, Epilepsy Alliance Europe, AES, NINDS, DG research and counterparts from Canada. This was highly successful with a commitment from all parties to take this forward toward funding of a global project.

Plans over the coming year will be to follow through on this initiative, developing it further, with publication of the report on the research priorities.

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)
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)
Sheryl Haut (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 2016 through June 2017

The following papers are completed (based on more than 300 included articles from a systematic review) and will be submitted to *Epilepsia*:

- Austin JK, Fernandes PT, Fiest KM, Ali A, Birbeck G, Braga P, Cross H, de Boer H, Dua T, Jacoby A, Mifsud J, Moshé S, Parko K, Tripathi M, Wiebe S, Haut S, Lorenzetti D and Jetté N. Instruments to measure epilepsy-related stigma and attitudes: Report from the International League Against Epilepsy Task Force on Stigma in Epilepsy. (to submit to *Epilepsia*)

- Birbeck GL, Parko KL, Fiest KM, Ali A, Austin J, Braga P, Cross H, de Boer H, Dua T, Fernandez P, Jacoby A, Mifsud J, Moshé S, Tripathi M, Wiebe S, Haut S, Lorenzetti D and Jetté N. Systematic review of intervention studies for stigma reduction in epilepsy: It is time to fill the vacuum. (to submit to *Epilepsia*)
- Two additional manuscripts are almost done. One led by A. Jacoby on frequency of stigma and factors associated with stigma in epilepsy. Finally, the last one on frequency of attitudes and factors associated with negative attitudes in epilepsy led by N. Jetté. All above papers are expected to be submitted by April 2017.

Recommendations for Future Work

- Establish recommendations for tools to measure stigma in epilepsy in younger patients and in the elderly
- 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 and would need to be addressed by a new task force, as several of our members have retired, etc.

Report by
Nathalie Jetté & Kirsten Fiest



Regional Commissions 2013-2017

COMMISSION ON AFRICAN AFFAIRS



Amadou Gallo Diop

Chair

Amadou Gallo Diop (Senegal)

Secretary General

Yacouba Njankouo Mapoure (Cameroon)

Treasurer

Angelina Kakooza (Uganda)

Education Officer

Jo Wilmshurst (South Africa)

Research Officer

Mesu'a-Kabwa (Pierre) Luabeya (DR Congo)

Communications Officer

Birinus Ezeala Adikaibe (Nigeria)

Members

Sammy Ohene (Ghana)

Executive Committee Liaison

J. Helen Cross (UK)

COMMISSION ON ASIAN AND OCEANIAN AFFAIRS



Byung-In Lee

As of December 2016, CAO A has 20 chapters in the Asian and Oceanian region, which includes Australia, Bangladesh, China, Hong Kong, India, Indonesia, Japan, Korea, Malaysia, Mongolia, Myanmar, Nepal, New Zealand, Pakistan, Philippines, Singapore, Sri Lanka, Taiwan, Thailand, and Vietnam.

Nomination and election of the CAO A 2013-2017 Office Bearers were carried out in the first and the second quarter of 2013. New members of CAO A took office officially in July 2013 and Co-chairs of CAO A-Research Task Force (A Ikeda and CT Tan), Chair of Regional Committee of GCAE (E Somerville), Chair of Pediatric TF (HD Kim), and Chair of Constitution TF (J Dunne) joined the commission as Ex-officios. In addition Dr. Derrick Chen (Singapore) recently joined the Commission as a co-chair of the Information Committee (ex-officio) from August 2014.

Chair

Byung-In Lee (Korea)

Members

Andrew Bleasel (Australia), Secretary
Leonor Cabral-Lim (Philippines), Treasurer
Sunao Kaneko (Japan), Information Officer
Man Mohan Mehndiratta (India)
Guoming Luan (China)
Kheng Seang Lim (Malaysia)
Tatsuya Tanaka (Japan) ILAE-First Vice President
John Dunne (Australia) Chair of ASEPA
Derrick Chan (Singapore) Co-chair of Information Committee

Task Forces

Constitution Task Force

John Dunne (Australia)

Research Task Force

Akio Ikeda (Japan)
Chong Tin Tan (Malaysia)

Global Campaign Task Force

Ernest Somerville (Australia)

Pediatric Task Force

Heung Dong Kim (South Korea)

ASEPA

The Asian Epilepsy Academy (ASEPA) was formed in 2003, initially as the educational arm and now a sub-commission of CAO A. From July 2015, Dr. SH

Lim(Singapore) finished his four year-term and Dr. JW Dunne (Australia) was newly appointed as the Chair of ASEPA. The past and current membership of ASEPA are shown below.

2011-2015:

Shih Hui Lim (Singapore), Chair
Man Mohan Mehndiratta (India), Member
Yushi Inoue (Japan), Member
Weiping Liao (China), Member
Dede Gunawan (Indonesia), Member
Byung-In Lee (Chair, CAO A), Ex-Officio

2015-2019:

John W. Dunne (Australia), Chair
Chong Tin Tan (Malaysia), Member
Weiping Liao (China), Member
Parthasarthy Satishchandra (India), Member
Kurnia Kusumastuti (Indonesia), Member
Zarine Mogal (Pakistan), Member
Derrick Chan Wei Shih (Singapore), Member
Byung-In Lee (Korea, Chair of CAO A), Ex-Officio
Shih Hui Lim (Singapore,
Immediate Past President, ASEPA), Ex-Officio

Aims and Missions of CAO A

Aims

Aims of CAO A, the regional commission of ILAE, are to develop, stimulate, and coordinate the epileptology agenda in the Asian and Oceanian regions.

Mission

- a. To advance and disseminate knowledge concerning the epilepsies throughout the Asian & Oceanian region;
- b. To improve education and training in the field of the epilepsies in Asia via the formation of the Asian Epilepsy Academy;
- c. To organize the Asian Oceanian Epilepsy Congresses together with the International Director of Meetings (IDM) and IBE's Regional Executive Committees;
- d. To facilitate clinically relevant epilepsy research in Asia;
- e. To serve as a link between ILAE, IBE, WHO, and regional medical organizations to promote prevention, diagnosis, treatment, advocacy and

COMMISSION ON ASIAN AND OCEANIAN AFFAIRS *(continued)*

care for all persons suffering from these disorders in the Asian and Oceanian region;

- f. To promote the activities of local chapters, encourage similar policies and administrative structures, and facilitate their involvement within the global ILAE agenda;
- g. To review epilepsy services and the size of the treatment gap in each country, and aim to improve the former and reduce the latter.

Action Plans of the CAO A: 2013-2017

Formulated in the CAO A business meeting at Seoul on September 26th, 2009, and newly added and revised at the business meeting at Seoul, September 27th, 2013.

1. Construct CAO A and ASEPA website with its link to ILAE website and regional Chapter's website, and publish newsletters
2. Enhance education and training in epileptology in the Region:
 - a. continue to provide teaching courses and workshops to regions in need
 - b. provide and expand epilepsy fellowship programs for the nurturing of future epilepsy specialists of the region
 - c. continue to provide EEG certification examinations and expand EEG teaching courses for the purpose of enhancing the standard of EEG recording and interpretation skills
3. Organize the Asian and Oceanian Epilepsy Congresses every two years.
4. Stimulate clinical and translational research
5. Promote new Chapter formation
6. Facilitate Global Campaign Against Epilepsy (GCAE) activities and try to implement CAO A demonstration projects for reduction of treatment gap in the region
7. Facilitate interactions and communications among Chapters and Commissions
8. Initiate the "Asian and Oceanian Outstanding Achievement Epilepsy Award"
9. Promote diagnosis and treatment of neonatal and childhood epilepsies in the region

Commission Activities

1) Communication and Business Meetings

Communication amongst members of CAO A and ASEPA were mainly through e-mails and during teaching courses/workshops/congresses in the region. Face-to-face business meetings of CAO A were held at least once a year.

- a. CAO A initiation business meeting was held on September 27th, 2013, at Lotte City Hotel Mappo in Seoul, Korea

The discussion points included (1) Progress reports of CAO A and adoption of new action plans for 2013-2017, (2) Progress reports of ASEPA (SH Lim), (3) Budget for 2013 (JJ Tsai), (4) Report of Research TF (CT Tan and A Ikeda), (5) Report of Information Committee (S. Kaneko), (6) Report of GCAE TF (E Somerville), (7) Report of Constitution TF (J Dunne), (8) Report of Pediatric TF (HD Kim), (9) Budget plan of 2014 (L Cabral-Lim), (10) Myanmar Project (E Somerville), (11) ASEPA Fellowships (CT Tan). The meeting was well summarized in the minutes (by J Dunne)

- b. Joint CAO A and ASEPA business meeting was held on August 6th, 2014, at the Waterfront Hotel in Singapore

The discussion points included (1) Report of CAO A activities (BI Lee), (2) Report of ASEPA activities (SH Lim), (3) Budget for 2014 (L Cabral-Lim), (4) Report of Information Committee (S Kaneko), (5) Report of Research TF (CT Tan and A Ikeda), (6) Report of GCAE-TF (E Somerville), (7) Report of Constitution TF (J Dunne), (8) Report of Pediatric TF (HD Kim), (9) Report of 10th AOEC (K Hodgson), (10) Message from ILAE (H Cross), (11) Report from Indian Epilepsy Society (MM Mehndiratta), (12) Venue for the 11th AOEC; presentation by applying chapters-Hong Kong chapter (C Lui) and Indonesian Chapter (K Kusmasututi), IDM Perspectives (R Holmes). The meeting was well summarized in the minutes (by A Bleasel).

- c. 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) Report of Treasurer (L Cabral-Lim), (3) Report of Research TF (CT Tan and A Ikeda), (4) Report of Information Committee (D Chan), (5) Report

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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).

- d. CAO-ASEPA Joint meeting was held on May 12th, 2016 at HKCEC in Hong Kong
- The discussion points included (1) Report of CAO activities (Bl Lee), (2) Report of ASEPA activities (SH Lim), (3) Budget for 2016 (L Cabral-Lim), (4) Report of Information Committee (S Kaneko), (5) Report of Research TF (CT Tan and A Ikeda), (6) Report of GCAE-TF (E Somerville), (7) Report of Constitution TF (J Dunne), (8) Report of Pediatric TF (HD Kim), (9) Report of 11th AOEC (K Hodgson), (10) Message from ILAE (H Cross), (11) Venue for the 12th AOEC by IDM Perspectives (R Holmes). The meeting was well summarized in the minutes (by A Bleasel).

2) Chapter Convention

- a. Aug. 7th, 2014 at the 10th AOEC in Singapore (Grand Copthorne Waterfront Hotel)
- (i) Report of CAO activities, budget and future plans, which were all approved
 - (ii) Messages from ILAE (by E Perucca and H Cross)
- b. May 13th, 2016 at the 11th AOEC in Hong Kong (the HKCEC)
- (i) Report of CAO activities, budget and future plans, which were all approved
 - (ii) Messages from ILAE (by E Perucca and H Cross)
 - (iii) Non-chapter delegates (Dr. Channara Chhour from Cambodia and Dr. Phetvongsinh Chivorakoun from Laos) were invited to the Chapter convention for future interactions

3) New Chapters

- a. Myanmar is the 20th chapter of CAO, which was approved at the IEC in Montreal, June 23rd-27th, 2013
- b. Application of Laos Chapter was submitted but at halt due to internal difficulties during the process of revision and translation of their bylaws
- c. Cambodia is in the process of preparing for a chapter application

4) Information Committee (Co-chairs: S Kaneko and D Chan)

At the Information Committee meeting in Singapore (at 10th AOEC), it was decided to appoint Dr. Derrick Chan as Co-Chair of the Information Committee not only to help and share the work with Dr. S Kaneko, but also to expand the scope of action.

- a. Organized a network consisting of information officers from each chapter
- b. Project 1. Construct and improve CAO-website
 - CAO-Website (<http://www.cao-epilepsy.org>) was opened in 2011 and its structures were remodeled and improved by ILAE-Recommendation
 - It is maintained by JSE on a monthly basis
 - Linkage between CAO website and that of each chapter
 - Include education and research-related matters (from AOEC and ASEPA)
 - Post-up programs of annual congresses or epilepsy-related events of individual chapters
 - Include minutes and annual report of CAO and ASEPA
- c. Project 2. Publication of CAO Newsletter twice a year
 - One issue in 2013 and 2014; two issues in 2015 and 2016
- d. Future Activities
 - Provide a platform for conferencing or discussions among CAO and ASEPA members
 - Encouraging communications among chapters
 - Archives from previous meetings, including AOECs and IECs
 - News and advocacy from individual chapters

5) CAO-RTF (Co-Chairs; A Ikeda and CT Tan)

- a. AO Research Priorities (by Kwan et al.) was published in *Epilepsia* (2015, 56: 667-673), which will be a guideline for future research in our region
- clarify health burden of epilepsy, particularly the treatment gap
 - Understand etiologies and epileptogenesis
 - Lessening psychosocial comorbidities
 - Achieve better treatment outcome
 - Improve research infrastructure

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- b. Organize sessions for Research TF and young investigators of our region at AOECs
 - A symposium of Leadership program at 11th AOEC
 - Presentation of two abstracts selected by RTF
- c. Ongoing joint research projects
 - AEDs and SJS by multichapter trials in Southeastern Asia
 - Relationship between public attitude and stigma in different communities
- d. Organized “Epilepsy Summer School” in collaboration with GCAE-TF and ASEPA

6) GCAE-TF (Chair; E Somerville)

- a. Encourage groups outside of official Global Campaign to speak at the 11th AOEC and ES linked to the “Action Against Untreated Epilepsy (AAUE)” run by an Irish Neurologist, Victor Patterson, operating a clinic in Nepal
 - Organize a session for “Global Campaign Forum” in AOECs for introduction and exchange of experiences of diverse activities across the region
- b. Myanmar project: Initiated to formulate a project in Mandalay through key neurologists and administrators of MOH. However, the project was on halt due to the replacement of key persons in MOH
 - ES moved Epilepsy Society of Australia (ESA) to provide “Observeships in Australia” for Myanmar epileptologists
 - Sent EEG technologists in Sydney for technical support of EEG in Yangon and Myanmar
- c. Laos project: The project is based upon that undertaken by the Frankphone Tropical Medicine Institute, where the CAOAs’ role is to provide education, mainly to train neurologists and thus help to make the project long-term sustainable
 - 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, which was unexpectedly delayed during the process of revision and translation

- d. ESA is providing Travel scholarship to attend EEG and Epilepsy Courses in Australia
 - 2015: Philippines x4, Myanmar x1, Laos x1
 - 2016: Cambodia x2, Laos x2, Philippines x2, Myanmar x1
- e. Organized an “Epilepsy Summer School” in collaboration with RTF (CT Tan) and ASEPA (J Dunne) on 13th to 16th, August (three days), at Banjarmasin in South Borneo, Indonesia
 - 65 registrants in the format of small group and interactive sessions
 - Organizer: Dr. K Kusumastuti, Dr. P Pambudi, Dr. E Somerville
 - Faculties: CT Tan, E Somerville, J Dunne, HD Kim, J Casanova-Gutierrez, Chong Wong, P Satishchandra, K Kusumastuti
 - Excellent response and feedback: planning to have the same course in May, 2017, in Matram (Lombok), Indonesia

7) Constitution Task Force (by J Dunne)

At present, the election of ILAE-President and Officers of the Management Committee were finished, which will be followed by the election of Chairs and members of Regional Commissions according to the Election Rules finalized by the Harmonization TF (Chair: H Cross). JD did provide the opinions of CAOAs to the Harmonization TF, which was approved by ILAE Exc.

8) Constitution Task Force (by J Dunne)

- a. Network formation among pediatric representatives in chapters of CAOAs
- b. Organized a “Session for Pediatric TF” and had a “Pediatric TF business meeting” at AOECs
 - Conduct ILAE pediatric commission activities to our region
 - Increase the number/proportion/quality of international exchange fellowship training
 - Handle treatment and educational gaps
- c. Develop new educational courses in collaboration with local chapters, ASEPA, and other related organizations
 - Korean Pediatric Epilepsy Preceptorship, China-Korea Pediatric Epilepsy Preceptorship, etc.
 - Involved with Epilepsy Summer School in Banjarmasin, Indonesia, 13th to 16th, August, 2016

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- Planning to have a collaboration with the 19th Annual Meeting of the ISS International Symposium on Status Epilepticus, July 17 - 19, 2017, in Marco Polo Plaza Hotel, Cebu City, Philippines. Pediatric experts meeting was held in Singapore after a pediatric parallel session on 8th Aug, 2014.

9) ASEPA Report (by John Dunne)

ASEPA, the educational arm of CAOAA (established in 2003), has been conducting enormous educational and training activities consisting of the following four Major activities;

a. Educational program consisting of Teaching courses and workshops:

- ~ 10 courses/ year, usually in resource-limited areas in collaboration with local epilepsy community

b. EEG Exam: Part I & II (led by SH Lim, mainly in ASEAN Countries)

c. Organize Sessions in AOECs:

- 2 - pre-congress courses
- 5 - didactic lectures
- M Seino's Memorial Lecture Publication of AOEC Proceedings

d. Fellowships:

- ASEPA fellowships: two people for six months/year
- Japan Epilepsy Research Foundation (JERF): 2-4 fellowships/year
- Visiting observerships or international travel

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a. Educational Programs

(a) Teaching Courses and Workshops in 2016. 7 -2016. 3.

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	7th and 8th 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	14th & 15th August 2015	J Dunne & WP Liao	E Somerville, J Dunne, C-S Chi, CT Tan, WP Liao
International Epilepsy Congress	Istanbul, Turkey		5th - 9th Sept 2015		
3. EEG Teaching Course (ANZAN Format – 2 days)	Guangzhou, China	CAAE & ASEPA	9th-10th 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 Foundation & ASEPA	Chittagong, Bangladesh	Bangladesh Epilepsy	20th- 21st Nov 2015 (deferred)	MA Mannan & SH Lim/J Dunne	Deferred To first quarter of 2016
5. Indian Epilepsy School EEG Certification examinations	Udaipur, India	IES & ASEPA	23rd-25th 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	23rd-25th October 2015	M Tripathi & SH Lim	KS Lim, CT Tan, S-J See, MM Mehndiratta
7. Clinical Epilepsy Workshop	Vientiane, Laos	ASEPA	7th-8th Jan	CT Tan and Dr Somchit	SH Lim, CT Tan, J Dunne, D Chan
8. Seizure Localisation Workshop	Vietnam	Local Chapter & ASEPA	5th-6th March	Le Van Tuan & J Dunne	S Harvey, W Maxmir, J Dunne, BI Lee
9. EEG Teaching Course (ANZAN Format – 2 days)	Indonesia	Local Chapter & ASEPA	TBA	?E Somerville	
10. Summer School – 3 days	Pedang, Indonesia	Local Chapter & ASEPA	TBA	CT Tan	
11. Epilepsy Syndrome Workshop Foundation & ASEPA	Chittagong, Bangladesh	Bangladesh Epilepsy	TBA	MA Mannan & SH Lim / J Dunne	
12. Epilepsy Syndrome Workshop	China	CAAE & ASEPA	TBA	J Dunne & WP Liao	
13. EEG Teaching Course (ANZAN Format – 2 days)	Chongqing, China	CAAE & ASEPA	TBA	J Dunne & WP Liao	
14. Publication workshop	China	CAAE & ASEPA	TBA	WP Liao & ASEPA	
AOEC	Hong Kong, China		13th - 16th May		
15. EEG Teaching Course (ANZAN Format – 2 days)	Colombo, Sri Lanka	Local Chapter & ASEPA	TBA		
16. Epilepsy Syndrome Workshop	Colombo, Sri Lanka	Local Chapter & ASEPA	TBA		
17. Epilepsy Syndrome Workshop	Pakistan	Local Chapter & ASEPA	TBA		
18. Pre Indian Epilepsy School – Pharmacotherapy workshop	Ludhiana, India	IES & ASEPA	26th-27th November	Gagandeep Singh & ASEPA (?P Kwan)	

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b. EEG Certification Exam (led by SH Lim since 2006)

(i) ASEPA-ASNA EEG Certification Examination
In collaboration with the ASEAN Neurological Association (ASNA) since 2005; for candidates from Asian Oceanian region except China & India

(ii) ASEPA-ASNA-CAAE EEG Certification Examination
In collaboration with China Association Against Epilepsy (CAAE) since 2009; for candidates in China

(iii) ASEPA-ASNA-IES EEG Certification Examination
In collaboration with Indian Epilepsy Society (IES); from 2012, for candidates in India

- EEG certification Exam consists of Part 1 and Part 2 Exam
 - Part I (2005-2014);
Total applicants = 608
Pass = 376 pass rate: 61.8%
 - Part II (2006-2014);
Total applicants = 338
Pass = 247 pass rate: 73.1%
 - Total: Pass Rate: ~ 40.7 %
 - Total since 16th November, 2006:
338 applicants and 247 passed (73.1%)

c. ASEPA Educational Courses at AOEC

(i) Three workshops:

- ASEPA Workshop: CHAPTER LEADERSHIP AND MANAGEMENT
Chairs: Shih Hui LIM (Singapore) and Chong Tin TAN (Malaysia)
- ASEPA Pre-congress Course 1 -
Diagnosis: Is it a Seizure?
Chairs; Shih Hui LIM (Singapore) and Ernest SOMERVILLE (Australia)
- ASEPA Pre-congress Course 2 -
Diagnosis: Localization of Seizures
Chairs: John DUNNE (Australia) and Byung-In LEE (South Korea)

(ii) Masakazu Seino's Memorial Lecture

- Akio IKEDA (Japan): "Exploring the mysteries of EEG: Can infraslow and DC shift improve epilepsy treatment?" Chairman: Shih Hui LIM

(iii) ASEPA Didactic Lectures

- Epilepsy and memory - Marco MULA (United Kingdom)
- Obesity, osteoporosis and epilepsy: Why and what to do? - Terry O'BRIEN (Australia)
- Epilepsy treatment - Can genetic tests guide us? - Weiping LIAO (China)

- Contemporary management of women with epilepsy across the lifespan - Torbjorn TOMSON (Sweden)

- Can I stop my drugs? (Management of the well-controlled patient) – Mark COOK (Australia)

d. ASEPA and other fellowships (led by CT Tan)

(i) ASEPA fellowships: 2 persons/year (stipend for 6mo/persons, \$7,000/ person)

- Two Awardees: Ma Le Quan from HCMC (Host Institution: Singapore General Hospital under supervision of SH Lim and SJ See) and Hnin Wint Wint Aung from Myanmar (Host Institution: University of Malaya under supervision of CT Tan)

(ii) Other fellowships

- Six travel grants were awarded to attend the clinical epilepsy and EEG course in Sydney in February, 2015. The Funding Source was Epilepsy Society of Australia and ANZAN. They were coordinated and decided upon through ASEPA
- 2015 Philippines x4, Myanmar, Laos
- 2016 Cambodia x2, Laos x2, Philippines x2, Myanmar
- From Japan, 2-3 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

e. ASEPA Strategic Plan for 2015-2019 (by J Dunne) An ongoing commitment to a flexible approach with:

- Defining educational objectives depending on target audience and local needs
- Educational course/workshops, with a format (didactic and/or interactive case-based) and content appropriate to the local needs, available resources and time
- Ongoing updating of the programme contents
- All workshops and courses continue to provide language-specific educational materials that are distributed to those attendants
- Feedback post-workshop (end of course surveys)
- Visiting professorship for 2-3 days following the workshop to provide mentoring in clinical skills, EEG or both. For example, Professor Somerville staying for three days after the Chifeng Epilepsy Syndrome workshop
- Ongoing recruitment of local colleagues to become involved in education and training efforts

COMMISSION ON ASIAN AND OCEANIAN AFFAIRS *(continued)*

- Ongoing educational supervision and mentoring; training and supporting the local educators via email and teleconferencing, strengthening the development of personal relationships and local teaching
- Follow-up consolidation workshop, usually within 2-3 years

(10) CAO A Collaboration with Other Related Organizations (AOCN, ASNA, AESC, & ISS)

- a. 15th AOCN in Kuala Lumpur on August 18-21, 2016
 - TC1: Epilepsy-EEG workshop-AOCN-ASEPA
 - TC2: Epilepsy-Presurgical Evaluation Workshop: Localization of epileptic zone and networks-AOCN-ASEPA
 - Epilepsy 1-The Joint symposium of AOCN and CAO A: Diagnosis and treatment of epilepsy What is epilepsy? A practical clinical definition of epilepsy
 - Epilepsy 2-The joint Symposium of AOCN and CAO A: Epilepsy in Neurocritical Care ILAE Definition and Classification of Status Epilepticus
- b. Joint symposium of CAO A and AESC
 - 9th AESC (Asian Epilepsy Surgery Congress) in Udaipur, India on Oct. 24-25th
Speakers; El Shon (Korea), J Stern (USA), M Tripathi (India), S. Liu (China)
 - 10th AESC on November 4th, 2017, Kyungwon-Jei, Songdo, Kyungki-do, Korea
Speakers: Byungin Lee (CAOA), Akio Ikeda (CAOA), Seung Chyul Hong (AESC) Yong Min Sohn (AESC)
- c. Collaboration with Other Epilepsy Organizations of the region in 2017
 - Planning to have a collaboration with the 19th Annual Meeting of the ISS International Symposium on Status Epilepticus, July 17-19, 2017, in Marco Polo Plaza Hotel, Cebu City, Philippines
 - Planning to have a collaboration with WFN (September) in Kyoto, Japan
 - Planning to have a collaboration with the 11th AESC (Shanghai, China)

(11) AOECs (by K Hodgson)

- a. 10th AOEC, 7th to 10th August, 2014, at the Grand Copthorn Waterfront Hotel in Singapore
 - SOC: Co-chairs: BI Lee, SH Lim, V Saxena
Members: T Tanaka, R Cole, D Chan, CT Tan

- There were 1,307 registrations from 49 countries.
 - Asian & Oceanian ILAE chapters and IBE members. The Tournament of the Brainwaves Quiz was a new feature to the programme
 - The Epilepsy & Society Symposium saw 150 attendees from Singapore and across the region. The Epilepsy & Society Symposium was rounded off with an innovative mini-fair.
 - In total, 400 abstracts were submitted, of which 40 were selected for platform sessions. The Tadokoro Prize was awarded to the two best poster and platform presentations
 - Out of 114 travel bursary submissions, 45 received a travel bursary.
- b. 11th AOEC, 13th to 16th, May, at the HKCEC in Hong Kong
 - 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
 - ~1200 registrations with the highest sponsorship achieved in this AOEC
 - 351 abstracts were submitted and 125 of them coming from China alone, however, 20% of Chinese abstracts were withdrawn due to ASA problems
 - 11th AOEC was widely reported in the news in HK both on TV and daily newspapers and Dr. KO Wingman, HongKong's Secretary of Health, visited twice during the congress
 - Feedback: Praise on the high-quality Scientific Program
 - c. 12th AOEC
 - Venue: 21st to 24th of June, 2018, Sanur Paradise Hotel in Bali, Indonesia
 - SOC: Chair Kurnia Kusumastuti (Indonesia) Parthasarthy Satishchandra (India), Byung-In LEE (Korea)
Members-J. Dunne (Australia), A. Yung (Hong Kong) KS. Lim (Malaysia), D. Ding (China), D. Champman (Australia), T. Tanaka (Japan)
 - Deadline for session proposals: 23rd September, 2016
 - Principal supporters of the 11th AOEC (Esai, UCB, GSK, Sanofi and Janssen) all committed to the 12th AOEC

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(12) Asian and Oceanian Outstanding Epilepsy Award (AOEA led by A Bleasel)

- a. Recipients at the 10th AOEC in Singapore:
 - Felicidad Soto (Philippines)
 - Ming-shung Su (Taiwan)
 - John Dunne (Australia)
 - Qifu Tan (China)
- b. Recipients at the 11th AOEC in Hong Kong:
 - Yuan-gui Huang (China)
 - Patrick Kwan (Australia)
 - KV Muralidharan (India)
 - Manjari Tripathi (India)

COMMISSION ON EASTERN MEDITERRANEAN AFFAIRS



Hassan Hosny

Chair

Hassan Hosny (Egypt)

Commission Members

Ahmad Beydoun (Lebanon), Past Chair
Raidah Al-Baradie (Saudi Arabia), Treasurer
Ghaïeb Aljandeel (Iraq)
Taoufik Alsaadi (Abu Dhabi)
Mohammed Al-Shehab (Jordan)
Amina Gargouri (Tunisia)
Ahmed Khalifa (Syria)
Emilio Perucca (Italy), Executive Committee Liaison

Aims and Missions

Aims

The main aim of the Commission on East Mediterranean Affairs is to develop, stimulate, and coordinate the epileptology agenda in the CEMA region.

Mission

- 1.To advance and disseminate knowledge concerning epilepsy throughout the CEMA region;
- 2.To organize the CEMA Epilepsy Congresses together with the International Director of Meetings (IDM) and IBE's Regional Executive Committees;
- 3.To facilitate clinically relevant epilepsy research in the CEMA region

- 4.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 CEMA region;
- 5.To promote the activities of local chapters

CEMA sponsored activities in 2016

- Tunis DEC 2015: two day EEG course
- Qatar FEB 2016: Annual Epilepsy meeting
- **Dubai May 2016: 3rd CEMA congress**
- Dammam November 2016: Annual Saudi Epilepsy Congress
- Kuwait December 2016: Annual Epilepsy Kuwaiti Lebanese Epilepsy meeting
- Luxor Pre-congress EEG course February 2017
- **Luxor February 2017: 4th CEMA Epilepsy congress**
- Tunis March 2017: Joint CEMA/African commission meeting



4th East Mediterranean Epilepsy Congress. Luxor, Egypt, February 2017.
More photos and full report: <http://www.ilae.org/Visitors/Congress/EMEC-4-2017-Luxor.cfm>

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 Trinka (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

MC liaison

Emilio Perucca (Italy)

CEA Activities for 2016

1. Revised CEA educational agenda. CEA-available funding is limited due the low surplus from the Stockholm-ECE, consequently:
 - a. Reduced funding for the CEA-Core Courses (CCC) to \$15,000 per course.
 - b. A migrating course will materialize only upon demand and secured local findings by the host chapter.
 - c. A selected non-core course will be supported as a CEA-Sponsored Course (CSA) up to \$5,000 per course.
2. Epilepsy Advocacy Europe (EAE) through a joint ILAE-IBE Task Force (JTF), 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 (JTF) to apply for EU grants.
3. Established a collaboration with the European Academy of Neurology (EAN). A joint CEA-EAN-WG was formed to substantiate this collaboration.
4. EAN-CEA joint symposia at the 2016-EAN, 2016-ECE and 2017-EAN congresses as well as a joint educational initiative in joint annual symposia/courses during and beyond the EAN and the ECE Congresses, as well as issuing joint guidelines.
5. CEA-EEMA (European Epilepsy Monitoring Unit Association) consensus on testing patients during seizures.
6. A call for CEA-sponsored courses/symposia during 2017 was issued on 15/2/2016 (submission deadline: 19/6/2016). The submitted applications were discussed at the CEA meeting

on 27/8/2016. Funding available will be limited due to the low surplus from the Stockholm-ECE.

The following courses will be supported by the CEA in 2017:

- CEA-Core Courses (CCC)
- EPODES-Advanced Epilepsy Surgery Course (Brno, 16-20/1)
- 7th Eilat Educational on Pharmacology Course (Jerusalem, 15-20/10)

CEA-Sponsored Activities (CSA)

- 4th International Course on Drug Resistant Epilepsies (Tagliacozzo, Italy, 7-13/5)
- 3rd East-European Course on Epilepsy (Bulgaria, 5-8/7)
- San-Servolo: Bridging Basic & Clinical (Venice, 9-21/7)
- 10th Baltic Sea Summer School (Tartu, Estonia, 6-11/8)
- 8th Caucasian Summer School (Dijian, Armenia, 13-18/9)

Activities and CEA Awards given at the 12th European Congress on Epileptology (ECE) in Prague (11-15/9/2016)

- European Chapter Convention on 11/9/2016 prior to the Prague-ECE 11/9/2016). Thus continuing an annual dialogue between the CEA & the various ILAE-European chapters.
- The CEA awarded travel bursaries to 42 young investigators (< 45 years) who submitted good abstracts.

CEA Awards given at the Prague-ECE

- European Epileptology Award (EUR 5,000):
P. Mares (Czech Republic) and F. Vigeveno (Italy)
- Non-monetary Awards
- European Education Award: N. Tatishvili (Georgia)
- European Young Investigator Award (<45 years)
J. Jacobs (Germany) and N. Specchio (Italy)

End of Term report: CEA Activities in 2013-2017

1. Issued (2014) and revised (2016) CEA educational agenda. CEA-available funding is limited due the low surplus from the Stockholm-ECE, consequently:
 - a. Reduced funding for the CEA-Core Courses (CCC) to \$15,000 per course.

COMMISSION ON EUROPEAN AFFAIRS *(continued)*

- b. A migrating course will materialize only upon demand and secured local findings by the host chapter.
 - c. Selected non-core courses will be supported as a CEA-Sponsored Course (CSA) up to \$5,000 per course.
2. Established an Epilepsy Advocacy Europe (EAE) through a joint ILAE-IBE Task Force (JTF), 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 (JTF) to apply for EU grants.
 3. Established a collaboration with the European Academy of Neurology (EAN). A joint CEA-EAN working group was formed to substantiate this collaboration.
 4. EAN-CEA joint symposia at the 2016-EAN, 2016-ECE and 2017-EAN congresses as well as a joint educational initiative in joint annual symposia/courses during and beyond the EAN and the ECE Congresses, as well as on coordinating guidelines.
 5. CEA-EEMA (European Epilepsy Monitoring Unit Association) consensus on testing patients during seizures.
 6. CEA-sponsored courses in 2017
A call for CEA-sponsored courses/symposia during 2017 was issued on 15/2/2016. The submitted applications were discussed at the CEA meeting on 27/8/2016. Funding available will be limited due the low surplus from the Stockholm-ECE.

The following courses will be supported by the CEA in 2017:

- CEA-Core Courses (CCC)
- EPODES-Advanced Epilepsy Surgery Course (Brno, 16-20/1)
- 7th Eilat Educational on Pharmacology Course (Jerusalem, 15-20/10)

CEA-Sponsored Activities (CSA)

- 4th International Course on Drug Resistant Epilepsies (Tagliacozzo, Italy, 7-13/5)
- 3rd East-European Course on Epilepsy (Bulgaria, 5-8/7)
- San-Servolo: Bridging Basic & Clinical (Venice, 9-21/7)
- 10th Baltic Sea Summer School (Tartu, Estonia, 6-11/8)
- 8th Caucasian Summer School (Dlijan, Armenia, 13-18/9)

Activities and CEA Awards given at the 12th European Congress on Epileptology (ECE) in Prague (11-15/9/2016)

- European Chapter Convention on 11/9/2016 prior to the Prague-ECE 11/9/2016). Thus, continuing an annual dialogue between the CEA & the various ILAE-European chapters. Publicizing and enabling pan-European initiatives such as ESBACE, EuroNash and EpiCare.
- The CEA awarded travel bursaries to 42 young investigators (< 45 years) who submitted good abstracts.

CEA Awards given at the Prague-ECE

- European Epileptology Award (EUR 5,000):
- P. Mares (Czech Republic and F. Vigevano (Italy)

Non-monetary Awards

- European Education Award: N. Tatishvili (Georgia)
- European Young Investigator Award (<45 years)
- J. Jacobs (Germany) and N. Specchio (Italy)

CEA-Sponsored Course/Symposia in 2016

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 (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)
- San-Servolo Course on Surgery (Venice, 17-28/7)
- 4th Neuropathology Summer School (Erlangen, 31/7-4/8)
- 2nd Inflammation & Immunity Conference (Milan, 13-15/10)

COMMISSION ON EUROPEAN AFFAIRS *(continued)*

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 in 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 2014

CEA-Core Courses (CCC)

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

CEA-Sponsored Activities (CSA)

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

CEA Activities for 2014

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

Non-monetary Awards

- a) European Education Award: I. Rektor (Czech Republic)
- b) European Young Investigator Award (<45 years): T. Ravizza (Italy) & S. Vulliemoz (Switzerland)
- c) European Service Award: V. Hezser-v Wehrs (Germany)
- d) Established at the ILAE- office in Dublin a repository of participants who received bursaries for CEA-sponsored courses from 2011 on.

COMMISSION ON LATIN AMERICAN AFFAIRS



Marco Medina

Chair

Marco Medina (Honduras)

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Laura Guilhoto (Brazil)
Lilia Maria Morales-Chacón (Cuba)

EC Liaison

Samuel Wiebe (Canada)

Task Force Members

**ALADE (Latin America Epilepsy Academy,
Academia Latino Americana de Epilepsia)**

Alejandro Scaramelli (Chair)
Elza Yacubian (Past Chair)
Patricio Abad (Secretary)
Roberto Caraballo (Argentina)
Jaime Carrizosa (Colombia)
Guilca Contreras
Li Li Min
Loreto Ríos
Alicia Bogacz (IBE Ex-Oficio member)

Epilepsy Surgery Task Force

Mario Alonso-Vanegas (Chair)
Manuel Campos (Chile)
Americo Sakamoto

LASSE (Latin America Summer School on Epilepsy)

Esper Cavalheiro (Chair)
Elza Yacubian (Brazil)
Fernando Cendes (Campinas, Brazil)

IX Latin American Epilepsy Congress, Cancún, Mexico

Gerardo Quiñonez, Chair
Tomas Mesa (Chile) Chair
Marco T Medina (Tegucigalpa, Honduras) Chair
Lilia Nunez S Orozco (Mexico)
Sam Wiebe (Canada)
Roberto Caraballo (Argentina)
Luz Reyes
Silvia Kochen
Franz Chaves Sell

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

Devora Kestel (Chair)
Carlos Acevedo
Marco T Medina
Jorge Rodriguez
Tomas Mesa

Primary Care Task Force

Lilia Maria Morales Chacón (Chair)

Research & Publications

Patricio Abad
Patricia Braga
Eduardo Barragán Pérez

Website

Franz Chaves Sell (Chair)

Aims

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

To provide and promote epilepsy care, education and research with excellence, quality, efficient and humanistic approaches for medical and health professionals in Latin America.

Commission activities from July 2014 through June 2015

1. A PAHO/ILAE/IBE Workshop on successful Latin American experiences was held in Tegucigalpa, Honduras on August 5th and 6th, 2015, with the support of the Faculty of Medical Sciences at the National Autonomous University of Honduras. A 2015 Technical report was published in Spanish and English (<http://www.ilae.org/Visitors/policy/documents/PAHO-report2016-English.pdf>). By 2016, two PAHO/WHO collaborative centers on epilepsy were established in Latin America (Chile and Honduras).

COMMISSION ON LATIN AMERICAN AFFAIRS *(continued)*

2. LASSE on February 21st to March 1st, 2016 in Sao Paulo, with the subject "Epilepsy in Latin America: The future ahead". During this LASSE course, a 10th anniversary was celebrated. More than 600 students from Latin America have participated between 2007 and 2016, and a follow-up project of these students is in the process of evaluation.
3. ALADE activities: Between 2015 and 2016, six epilepsy fellowships were awarded (three per year). ALADE Educational courses were carried-out in: a) Santa Cruz, Bolivia b) Managua, Nicaragua and c) San Salvador, El Salvador.
4. An agreement was made between the Pan-American Federation of Neurological Societies and the ILAE Commission on Latin American Affairs in order to promote regional neurological education.
5. The organizing committee of the IX Latin American Epilepsy Congress held in Cancun, Mexico, August 20-23, 2016 was working on educational activities. More than 800 participants were expected.
6. The ILAE Spanish website ("*Epilepsia en Español*") and the ILAE Portuguese website (ILAE in Portuguese) are very active (See at: http://www.ilae.org/Visitors/Centre/Trans_Spanish.cfm and http://www.ilae.org/Visitors/Centre/Trans_Portuguese.cfm.)
7. New regional Sub-commissions in genetics and diagnosis are in the process of being established.
8. Epilepsy Surgery Program was started in Bolivia in 2016. 9. An Epilepsy Primary Care Program was established in Bolivia, Honduras and Paraguay.

Accomplishments (2014-2015)

1. A PAHO/ILAE/IBE Workshop on successful Latin American experiences in 2015.
2. A PAHO/ILAE/IBE Technical document on Epilepsy in Latin America published in 2015.
3. Two approved WHO collaborative epilepsy centers in Latin America.
4. 10th anniversary (2007-2016) of the Latin American Summer School on Epilepsy with more than 600 students from our region.
5. Successful regional fellowship program.
6. ALADE educational activities in Bolivia, El Salvador and Nicaragua.
7. New Regional Epilepsy Primary Care programs.

Recommendations for Future Work

1. Long-Term evaluation of the PAHO Strategy and Plan of Action on Epilepsy.
2. Follow-up of the LASSE students and ALADE fellowship program.
3. Improve regional research projects.
4. Promote Epilepsy Primary Care regional programs also considered. Fun was also to be had, with tango dancing. There were many opportunities for discussion and networking.

Submitted by

Marco T. Medina and Franz Chaves-Sell

COMMISSION ON NORTH AMERICAN AFFAIRS



Sheryl Haut

Members

Sheryl Haut (USA), Chair
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Dave Clarke (USA/Caribbean)
Vicente Iragui (USA)
Jaideep Kapur (USA)
Solomon Moshé (Canada), EC Liason

AES Presidents Elson So (USA; 2013-2014);
Amy Brooks-Kayal (USA; 2014-2015);
Michael Privitera (USA; 2015-2016)

CLAE Presidents Nizam Ahmed (Canada; 2013-2014);
Nathalie Jette (Canada; 2014-2016)

CES Presidents Dave Clarke (2013-2015);
David Corbin (2015-2016)

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

Harmonization of Regulatory Activities

Jacqueline French (Chair) with international members Alexi Arzimanaglou (France), Emilia Bagiella (Mount Sinai), 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 Trinkka (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), Marco DeCurtis (LASSE)

Caribbean Task Force

Initial Board: Dave Clarke (President) and members (all from Caribbean) Amza Ali, Remy Bellance, Meshay 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, Dave Clarke (immediate past president)

Hispaniola Task Force

Lionel Carmant (Chair)

ICD-11 Working Group

(NARC in collaboration with Classification Commission)

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

Stigma Task Force

Nathalie Jette (Chair) and with 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 Moshe (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 groups 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 from June 2013 through June 2016

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

COMMISSION ON NORTH AMERICAN AFFAIRS *(continued)*

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) were finalized and dissemination will continue.

Intercommission Educational Outreach

The PECA program continued to support partnerships between epilepsy centers in the Americas to promote education and improvements in epilepsy care. >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

A new collaborative global health program will be created instead that will expand the scope of this initiative and provide a greater educational component to various regions rather than ongoing collaborations to ensure sustainability, etc.

Harmonization of Regulatory Activities

The task force on regulatory activities was very productive during this term. 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 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.

Publication: Mintzer S*, French J*, Perucca E, Cramer J; Messenheimer J, Blum D, Rogawsk M, Baulac M. (*shared first authors) Is a separate monotherapy indication warranted for antiepileptic drugs? 2015 *Lancet Neurology*, 14: 1229–40.

Recommendations for Future Work

A joint US-European meeting was planned in Prague for September 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.

The first leadership course held in conjunction with the International Epilepsy Congress in Istanbul in September 2015 was a success. A class of 21 impressive participants representing every ILAE region enrolled in the two-day training program that included a networking lunch with the ILAE Executive Team at the International Epilepsy Congress Meeting. 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

Planning is underway for the next program in Barcelona in 2017, and the program will be expanded 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 its 4th biennial meeting in St. Lucia in 2014. The meeting was a success. The task force succeeded in obtaining an EEG machine (donated from Global Diagnostics) for St. Lucia. They also implemented some clinical

COMMISSION ON NORTH AMERICAN AFFAIRS *(continued)*

care audits in a variety of centers. News and media initiatives took place in 2013-2014 to address epilepsy misconceptions with the general public. The task force also lobbied for new AEDs to be available at no cost to patients, and they were successful in getting several AEDs on the formulary. A social driving initiative was also created in collaboration with the International Foundation of Applied Disability; the aim of this initiative will be to go to the government to lobby for new laws for drivers with epilepsy.

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, nurse and physician talks. All were very well attended and interactive.

The 5th NARCCE meeting was held from March 3-5, 2016 in Barbados with stellar speakers from North America and the Caribbean.

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
- Kruss 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.

Recommendations for Future Work

The group will continue their work to improve education and clinical care in the Caribbean with their local members, but also with international collaborators including but not limited to other North American regions.

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 the 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.

A group of colleagues of Dr. Carmant also planned a three-day training session in the region (Drs. Anne Lortie, Dang Nguyen, Alexander Weil and Sylvain Chouinard) in 2016.

Recommendations for Future Work

Part two 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 three-day training session in the region (Drs. Anne Lortie, Dang Nguyen, Alexander Weil and Sylvain Chouinard).

ICD-11 Working Group

This new working group was established in 2013-2014 with the aim of preparing a document addressing conversion from ICD-9-CM in the US to ICD-10. The group met on a few occasions (IEC Montreal 2013, etc.) to discuss the paper and completed its task. The paper is called: ICD coding for epilepsy: Past, present

COMMISSION ON NORTH AMERICAN AFFAIRS *(continued)*

and future – a report by the International League Against Epilepsy Task Force on ICD codes in epilepsy. It is in press in *Epilepsia*.

Publication: Jetté N, Beghi E, Hesdorffer D, Moshe SL, Zuberi SM, Medina MT and Bergen D. ICD coding for epilepsy: Past, present and future – A report by the International League Against Epilepsy Task Force on ICD codes in epilepsy. *Epilepsia* 2015 Mar; 56(3):348-355.

Recommendations for Future Work

The aim was completed. Group members will continue to be involved collaboratively with WHO members to assist in field testing the proposed ICD-11 classification of the WHO and providing feedback to ensure the upcoming classification is aligned with developments in the epilepsy field.

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 early 2017. These will highlight gaps in the area of stigma in epilepsy research and provide recommendations for future research.

PAHO Working Group

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

In 2014-2015, 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.

The North American Commission Symposium

North American Commission/Commission on European Affairs Symposium in Washington, DC in December 2013: The symposium was chaired by S.Haut/N. Jette and M. Bialer. Topics included: (1) Setting standards: International collaboration for pediatric epilepsy surgery through the ILAE (G. Mathern, USA); (2) International pregnancy registries: A global approach to a global challenge (T. Thomson, Sweden); (3) International clinical trials – Threats and opportunities (E. Trinko, Austria); and (4) Epilepsy, big data and international research (B. Litt, USA).

North American Commission Symposium in Seattle, WA in December 2014: Pediatric epilepsy surgery: Update on Current Practice. Topic included: (1) What is pediatric epilepsy surgery? Gary Mathern; (2) What is so special about children? J. Helen Cross; (3) Pediatric epilepsy surgery: Is it only rare syndromes? William D. Gaillard; (4) What is the role of social media and nonprofits? Adam Hartman

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 (UK)

Commission Members

Nerses Bebek (Turkey)
Robert Fisher (USA)
Jackie French (USA)
Edouard Hirsch (France)
Jukka Peltola (Finland)
Kate Riney (Australia), Treasurer
Eliane Roulet Perez (Switzerland)
Muhammad Salisu (Nigeria)
Nobukasu Nakasato (Japan)
Ingrid Scheffer (Australia), Secretary
Nico Moshe (USA), Liaison with Executive

Task Force on Classification

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

Task Force on Seizure Types

Robert Fisher (USA), Task Force Chair
Norimichi Higurashi (Japan)
Floor Jansen (Netherlands)
Lieven Lagae (Belgium)
Sameer Zuberi (United Kingdom)
Ingrid Scheffer (Australia)
Helen Cross (United Kingdom)
Nico Moshe (United States)
Edouard Hirsch (France)
Jackie French (USA)
Eliane Roulet Perez (Switzerland)

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)
Muhammad Salisu (Nigeria)
Lieven Lagae (Belgium)
John Paul Leach (United Kingdom)
Rima Nabbout (France)
Ingrid Scheffer (Australia)
Elizabeth Thiele (United States)
Federico Vigeveno (Italy)
Khaled Zamel (United Arab Emirates)
Sameer Zuberi (United Kingdom)
Mike Kerr (United Kingdom)
Liaison to Commission on Neuropsychobiology

Aims

1. To develop the classification of seizures and epilepsies to reflect scientific advances in the understanding of the etiology of epilepsies, epilepsy syndromes and their associated co-morbidities.
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.
5. To develop a scientifically-based approach to the classification of seizures and the epilepsies, and to improve the diagnosis of epileptic seizures and syndromes globally.

Commission activities from July 2014 through June 2015

Task Force on Classification & Task Force on Seizure Types

These Task Forces worked in parallel together to develop the 2017 Classification of Seizures and the Epilepsies. This has involved many meetings at ILAE Congresses, teleconferences and email communications. Work in 2016 was intensive with papers published online in *Epilepsia*, in *Epilepsy Open* and on the ILAE website. Presentations were made at the ECE in Prague, at the AES and at several other national and regional meetings. This intensive

COMMISSION ON CLASSIFICATION AND TERMINOLOGY *(continued)*

engagement with the epilepsy community allowed The Classification and Seizure Type documents to be designated as ILAE Position papers. The Presidential Symposium at the ICE Barcelona will be “A New Classification is Born.” Three papers will be published in *Epilepsia* in February 2017. The titles of the papers are: 1. ILAE Classification of the Epilepsies: Position Paper of the ILAE Commission for Classification and Terminology 2. Operational Classification of Seizure Types by the International League Against Epilepsy 3. Instruction Manual for the ILAE 2017 Operational Classification of Seizure Types

Task Force on Neonatal Seizures

The Task Force has undertaken a systematic review to analyze the literature on the clinical semiology and electrographic features of neonates with proven seizures, and to correlate those findings with etiology of seizures and neurological outcome. 177 full texts were read and 57 studies were included in the review, which included papers from 2004-16. A report detailing the review (lead author Magda Lahorgue Nunes) will be ready for submission in 2017. The Task Force is preparing a manuscript (lead author Ronit Pressler) “Seizures in the Neonatal Period: Integration with the 2017 ILAE Classification of Seizures and Epilepsies” detailing the progress to date in developing a neonatal seizure classification. At the ECE in Prague 2016, a video presentation at the ILAE stall invited participants to view a proposed classification of neonatal seizures and then use it to classify videos presented. The Task Force to date has reviewed >1,600 neonatal EEG recordings from two participating centres with clinical and electrical seizures identified in >250 recordings. This resource will be used to develop and test the new neonatal classification.

Task force on Syndromes & EpilepsyDiagnosis.org

Although there is much information on the internet about epilepsy and seizures, there is a glaring absence of a single source of information that aligns with the international classification, and provides an organized presentation of the many seizure types and syndromes to help with diagnosis and treatment. This information gap was recognized and led to the ILAE’s EpilepsyDiagnosis.org project. It has been a unique resource in medicine and has harnessed the power of the internet to present the complexity of the significant amount of new information now available about the epilepsies and their etiologies, in a manner that is

concise, current and accessible to a global audience. It is as relevant to those in primary and secondary health care settings as it is to those in tertiary epileptology practice. It is also showing promise as an instructional and training resource for those who are new to medicine.

Since the release of EpilepsyDiagnosis.org, its reach has steadily increased, month over month. Currently, approximately 10,000 unique visitors access the site each month from around the world, viewing EpilepsyDiagnosis.Org pages more than 40,000 times per month. Users of the website span professional groups that range from those in primary care to those working in tertiary health care settings (Table 1). The ongoing growth in user engagement with EpilepsyDiagnosis.org continues to occur ‘organically’, through relevance of the website content to those in clinical practices where epilepsy is diagnosed, and managed. Around 4,000 people have registered to view the videos online.

Goals

The goals of EpilepsyDiagnosis.org are:

- to make available, in an easy to understand form, the latest concepts relating to seizures and the epilepsies.
- to assist clinicians, particularly those in primary and secondary health care settings anywhere in the world, who look after people with epilepsy to diagnose seizure type(s), classify epilepsy, diagnose epilepsy syndromes and define the etiology.
- to provide an educational resource that is current for personal learning and small group teaching settings.

What you will find on the EpilepsyDiagnosis.org website

The structure of the site reflects the importance of seizure type, syndrome, and etiology in clinical practice, and how these aspects of the epilepsy inter-relate. On the site you will find:

- seizure type classification with video examples of seizure types – the availability of video is a unique feature of this site, allowing clinicians to clearly see the features of seizures, including distinguishing features from other similar seizure types. A short and instantaneous registration process is required to view the video section and this is open to anyone, anywhere in the world with an internet connection.

COMMISSION ON CLASSIFICATION AND TERMINOLOGY *(continued)*

Individuals and their families have kindly given consent for videos to be freely available in this way.

- seizure types presented with differential diagnoses, including a comprehensive section on epilepsy imitators – where you will find full descriptions of non-epileptic paroxysmal phenomena that can mimic seizures.
- focal seizure types flexibly described by their features, and by features that suggest anatomical localization .
- epilepsy syndromes presented in a comprehensive list, including details on their clinical presentations, EEG and imaging features (with images to illustrate these) and current understanding of syndrome etiologies.
- epilepsy etiologies presented in a comprehensive but concise section that includes most notably genetic and structural etiologies, but also including content on metabolic and immune etiologies.

The etiology section provides concise and clinically relevant information on phenotypes seen with more than 50 genes associated with epilepsy, as well as the phenotypes seen in chromosomal abnormalities associated with epilepsy. In 2016, a significant upgrade has occurred to the structural etiologies content, making available the most current knowledge regarding brain abnormalities associated with epilepsy, especially newer information regarding their genetic bases. This section includes an extensive neuroimaging resource.

EpilepsyDiagnosis.org complements resources available through *Epileptic Disorders*, the ILAE's official educational journal, for professionals with particular interest in epilepsy. However, EpilepsyDiagnosis.org through its open access format, also provides an increased reach to health professionals from primary and secondary health care settings who see patients with epilepsy, and is relevant for community organizations and for the general public due to the simple and clear presentation of information.

Visitors to EpilepsyDiagnosis.org by professional background (top 10, accounting for 52% of all visitors)

- Secondary Health Care - Adult Neurology 8%
- Secondary Health Care - Pediatrics General 7%
- Postgraduate Medical Trainee - Adult Medicine 6%
- Secondary Health Care - Pediatric Neurology 6%
- Tertiary Health Care - Pediatric Neurology 6%
- Tertiary Health Care - Adult Neurology 5%

- Primary Health Care – General Practice 4%
- Postgraduate Medical Trainee - Pediatric Medicine 4%
- Primary Health Care - Other 4%
- Tertiary Health Care - Pediatric Epileptologist 4%

Accomplishments (2014-2015)

The accomplishments of the Commission are demonstrated by the breadth of work undertaken by the four Task Forces within the Commission. The Task Forces have worked within a consistent framework to deliver the aims of the Commission. The headline accomplishment is the publication of the first new official ILAE Classification of Seizure Types and the Epilepsies for 28 years. This is the culmination of the work of many individuals, Commissions and Task Forces over the last 28 years, and has only been possible through the active engagement of the international epilepsy community whose comments have developed and refined the 2017 Classification. EpilepsyDiagnosis.org has developed into the flagship educational resource of the ILAE and through continuing development and updating will be an invaluable teaching and diagnostic resource for clinicians and people with epilepsy. EpilepsyDiagnosis.org will play a key role in disseminating the concepts, terminology and structure of the 2017 classification.

Recommendations for Future Work

In 2017, the ILAE will publish companion Position Papers in *Epilepsia*; "The ILAE Classification of the Epilepsies" and "The Operational Classification of Seizure Types by the International League Against Epilepsy." These landmark papers represent the work of many Task Forces and Commissions since 1989. The Commission 2017-21 will need to take a proactive role in relation to education and dissemination of the 2017 Classification, and a reactive role to deal with the inevitable large volume of comments such important documents will receive. The ILAE Classification will have to be supported and at times defended by the new Commission. There needs to be a strong group that takes responsibility for the Classification and have an investment in defending, supporting and if necessary making (we hope minor) changes if unexpected issues emerge with the widespread use of the classification. The Commission will have to relate to other groups who request guidance and clarification on how to use the new classification. These include WHO & ICD, industry, regulatory authorities, neuroscientists and

COMMISSION ON CLASSIFICATION AND TERMINOLOGY *(continued)*

other clinical groups who use classifications to meet their specific needs.

We propose that the Commission 2017-21 comprises individuals (including the immediate past Chairs of the Task Forces and Commission) who will provide continuity and awareness of the processes leading to the new classification. It is for the incoming Chair of the Commission and ILAE Management Committee to set key priorities for the next term. However, developments in the new classification, incorporating major changes to the epilepsy lexicon and emphasizing etiology at all levels, will help define the agenda. This and advances in molecular genetics, imaging and metabolomics are changing our concepts of what comprises an Epilepsy Syndrome. A key task for the new Commission will be to develop our concepts of syndromes and to focus on further defining the etiological groups within classification.

Classification of Neonatal Seizures Task Force

The Commission through this Task Force are integrating neonatal seizure classification into the ILAE classification. The adult and childhood classification has developed over three Commission terms. We would ask this Task Force be allowed to continue for 1-2 years (unfunded) into the next term to complete their task. Concepts developed may act as a model for seizure classification due to acute causes and for seizures in the ICU setting in adults and children.

EpilepsyDiagnosis.org & Syndromes Task Force

EpilepsyDiagnosis.org was launched during this Commission's term and has been remarkably successful with 40,000 visits per month from 10,000 unique visitors. It will educate on the new classification and will require ongoing updating and development. The work required to maintain and develop the site is a key role for this Task Force, alongside developing concepts on what an Epilepsy syndrome means in the 21st century.

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 Tegueu (Cameroon)
Riki Matsumoto (Japan)
Donald Schomer (USA)
Sarah Wilson (Australia)

MC Liaison

Samuel Wiebe (Canada)

Task Forces

Task Force for Neuroimaging

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

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)
Riki Matsumoto (Japan)
Cigdem Özkara (Turkey)
Andre Palmieri (Brazil)
Donald Schomer (USA)
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)
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 (NL)
Sallie Baxendale (UK)
Sandor Beniczky (DK)
Fernando Cendes (Brazil)
Simon Keller (UK)
Riki Matsumoto (Japan)
Sarah Wilson (AUS)

Objectives

The Commission's aim is to provide standardized protocols, harmonize terminology use and develop guidelines for a cost-effective diagnosis of epilepsy, as well as use of consensus classification systems for underlying etiologies. Our Task Forces cover all major diagnostic modalities. Particular emphasis of this term's mission is to bridge the validation gap when using advanced, as well as standardized technologies, for the diagnosis of epilepsy, namely neurophysiology, neuropsychology, neuroimaging and neuropathology. Another important topic of our commission is to offer state-of-the-art teaching courses addressing WHAT? – evidence-based practice in core competencies relevant to the discipline; WHY? – to support the establishment of guidelines for minimum practice standards around

COMMISSION ON DIAGNOSTIC METHODS *(continued)*

the globe to improve the quality of care for people with epilepsy; and HOW? – by bringing together relevant healthcare professionals and early career researchers and clinicians from around the globe, including resource poor countries, to undertake intensive learning and training in the relevant discipline, accessible for ILAE members throughout the world. All ongoing activities as well as information from past activities can be viewed or downloaded from our newly designed website (<http://www.ilae.org/Commission/dm/index.cfm>).

Task Force for Neuropathology

A fifth edition of the WHO classification of tumors of the central nervous system was released in May 2016. The introduction of an integrated genotype-phenotype classification of gliomas and embryonal brain tumors already has clinical impact on diagnosis and treatment. However, integrated diagnostic genotype-phenotype criteria for low-grade epilepsy-associated brain tumors (LEAT) are not available and this field

continues to fall behind the rapidly developing area. This term's mission of the Neuropathology Task Force is, therefore, to help developing improved diagnostic criteria of LEAT. We completed five international agreement studies using a collaborative virtual microscopy platform, and developed an integrated genotype-phenotype classification for gangliogliomas and dysembryoplastic neuroepithelial tumors. Results of this new approach will be published in 2017. A recommendation for standardized neuropathological work-up of epilepsy surgery specimens has already been published (Blumcke et al. *Epilepsia* 2016). Our work was disseminated by the ongoing series of annual Neuropathology Summer Schools in West China Hospital, Chengdu, August 29th – September 1st, 2016 (see Lie and Blumcke, *Epilepsia* Gray Matter – in press), and Erlangen, Germany (October 6-9, 2016). Two 4-day neuropathology training courses will be offered in 2017 at Cleveland Clinic, USA, and UniCamp, Brazil (please see website for further information).

Fourth Advanced International Neuropathology and Epilepsy Surgery Course 2016.8.29 Cheng Du



COMMISSION ON DIAGNOSTIC METHODS *(continued)*

Task Force for Neuropsychology

The mission of the Neuropsychology Task Force is to provide knowledge for standardized use of neuropsychology measures in clinical practice and 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). A second report on Neuropsychological measures particularly helpful in epilepsy surgery will be completed early in 2017. The Task Force has successfully organized a first training course on neuropsychology and epilepsy in France, April 10-15, 2016 (Wilson SJ. Commentary on the 1st International Training Course on Neuropsychology in Epilepsy held

in Normandy, France, April 10-15, 2016. *Epilepsia*, 57, 1521-1530, 2016). A second training course is announced for 2018. Please see our website for further information. In addition, the Task Force has organized a Special Issue for the journal, *Epilepsy & Behavior*, entitled "The new approach to classification: Rethinking cognition and behavior in epilepsy." This special issue includes commentaries, review papers and empirical studies by Task Force members reflecting on the impact of the new approach to classifying the epilepsies, released by the ILAE Commission on Classification and Terminology, on our understanding of cognition and behavior in epilepsy. They have also recently contributed to a Special Interest Group at the AES meeting in Houston on Diagnostic and management challenges in psychosocial comorbidities: Complex clinical cases.



COMMISSION ON DIAGNOSTIC METHODS *(continued)*

Task Force for Neurophysiology

A major goal of this term's Neurophysiology Task Force is to provide international consensus recommendations on WHAT? WHY? and HOW? to apply intracranial EEG (IEEG) investigations. A recommendation manuscript entitled: "Diagnostic Utility of Invasive EEG for Epilepsy Surgery: Indications, modalities and techniques," has been published in *Epilepsia* 57(11):1735-1747, 2016. A work on recording and stimulation methodologies, based on

an already available survey (51 centers, 10 countries, three continents) is in progress and should be finalized in 2017. The Neurophysiology Task Force also aims at promoting training for surface and intracranial EEG. This knowledge is disseminated by the ongoing series of European and North-American SEEG courses that will be complemented in 2017 by a SEEG course in Asia (Singapore, April 21-24, 2017). An advanced training course dedicated to EEG in neonates is in preparation and will be available in 2018 (please follow updates at our website for further information).



North-american SEEG training course, Montreal

Task Force for Neuroimaging

The TF has focused on recommendations for the use of MRI in epilepsy care, with the purpose of updating current guidelines according to new clinical challenges and research findings, taking into account new developments on hardware and sequences. The group has drafted a set of recommendations broad enough to assist health care clinicians in established epilepsy centers and community settings. This knowledge will be disseminated by a 1st ILAE Summer School on Neuroimaging in 2017 (Montreal, May 18-21, 2017). This training and teaching facility will help to put these recommendations in practice. Please see our website for further information. Our projects will be supported by a newly developed web-based collaborative MRI reading

and teaching platform. A prototype is available and a proof-of-concept study addressing MRI signatures to distinguish ganglioglioma from DNT will be launched in 2017. Members of the Neuroimaging Task Force were involved in didactic activities at the annual meeting of the American Epilepsy Society in Houston (Special interest groups in neuroimaging and frontal lobe).

Attendees at the full-day business meeting in Houston

Saturday, Dec 3rd, 2017

Ingmar Blumcke (Germany)
Fernando Cendes (Brazil)
Andrea Bernasconi (Canada)
Sarah Wilson (Australia)

COMMISSION ON DIAGNOSTIC METHODS *(continued)*

Donald Schomer (USA)
Philippe Kahane (France)
Riki Matsumoto (Japan)
Sam Wiebe (Canada)
Richard Hogan (USA)
Matthias Koepp (UK)
Angelo Labate (Italy)
William Theodore (USA)
Eleonora Aronica (Netherlands)
Maria Thom (UK)
Hajime Miyata (Japan)
Harvey Sarnat (Canada)
Francois Dubeau (Canada)
Cigdem Özkara (Turkey)
Jean Gotman (Canada)
Demetrios Velis (Netherlands)
Prasanna Jayakar (USA)
Andreas Alexopoulos (USA)
Christoph Helmstaedter (Germany)
Bruce Hermann (USA)
Gus Baker (UK)
Sallie Baxendale (UK)
Mary-Lou Smith (Canada)
Severine Samson (France)
Sherifa Hamed (Egypt)

Guests

Stefan Rampp (Germany)
Jonathan Halford (USA)

Commission on Diagnostic Methods Continuity Plan 2017

Task Force for Neuropathology

This term's mission of the Neuropathology Task Force is to help developing improved diagnostic criteria of low-grade epilepsy-associated brain tumors (LEAT). We completed five international agreement studies using a collaborative virtual microscopy platform, and developed an integrated genotype-phenotype classification for ganglioglioma (GG) and dysembryoplastic neuroepithelial tumors (DNT). Results of this new approach and proposal will be published in 2017. An open-invitation international



agreement study testing reliability and practicability of the new ILAE-WHO proposal is envisaged for next term.

The new LEAT as well as previous classification systems for HS and FCD will be further disseminated by the ongoing series of annual Neuropathology Summer Schools in 2017 at Cleveland Clinic, USA, April 27-30, and UniCamp, Brazil, July 22-25 (please see website for further information).

Task Force for Neuropsychology

The mission of the Neuropsychology Task Force is to provide knowledge for standardized use of neuropsychology measures in clinical practice and to be understandable for epileptologists when using or interpreting different test domains. A second report on Indications and expectations for neuropsychological assessment in epilepsy surgery in children and adults is in preparation and will be submitted for publication in 2017. We also envisage a White Paper asking "What should neuropsychology look like in ten years' time?" Another major effort of this TF will be to develop an international collaborative research project culminating in the generation of evidence based and validated algorithms that estimate the risk of postoperative cognitive decline for temporal lobe surgery patients. It is envisaged that these algorithms will be made available on the ILAE website for all clinicians by the end of next term. A second International Training Course on Neuropsychology in Epilepsy will be organized in April 2018 (same venue as in 2016).

Task Force for Neurophysiology

The next term's goal of the TF should be to achieve synergism with the International Federation of Clinical Neurophysiology (IFCN). We suggest to appoint joint taskforces (ILAE-IFCN).

New guidelines should be negotiated between, and promoted by, both societies. Simultaneous publication of the guidelines from the joint taskforces in *Epilepsia* and *Clinical Neurophysiology* would help to maintain synergistic momentum.

Proposed topics for new guidelines (one joint taskforce for each topic):

1. Minimum standards for EEG recording for patients with (suspected) epilepsy
2. Minimum standards for long-term video-EEG monitoring (here has been a guideline on 1+2, but much outdated, by now)

COMMISSION ON DIAGNOSTIC METHODS *(continued)*

3. Electromagnetic source imaging
4. Transcranial magnetic stimulation and transcranial direct current stimulation in patients with epilepsy
5. Seizure detection

Task Force for Neurophysiology

The group has drafted a set of recommendations broad enough to assist health care clinicians in established epilepsy centers and community settings. A publication is envisaged for 2017. This knowledge will be disseminated by a 1st ILAE Summer School on Neuroimaging in 2017 (Montreal, May 18-21, 2017). The TF has developed a web-based collaborative MRI reading and teaching platform. A prototype is available and a first proof-of-concept study on MRI signatures to distinguish GG from DNT will be launched in 2017. The platform should be further implemented into a new set of web-based long-distance continuous medical education programs on MRI reading and diagnosis in epilepsy.

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)
 Günter Krämer (Switzerland)
 Daliwonga Magazi (South Africa)
 Hiba Mahmud (Pakistan)

MC Liaison

Samuel Wiebe (Canada)

Commission Activities June 2013 through September 2017

A. VIREPA

Following the transitional period 2009-2013, during which the original EUREPA program was transformed into VIREPA, the official ILAE distant education program, it was envisaged to continue and even expand the program, including some new courses that had been developed for this

purpose. Some courses, however, turned out to attract too few students and thus had to be cancelled. This included the “Mother of all VIREPA Courses”, the one on genetics, as well as the well-established courses on Imaging and on Medical Treatment, but also the newly developed courses on Epilepsy and Sleep and on Psychiatric aspects.

The EEG courses on the other hand continued to be extremely successful with, Basic EEG actually running two courses per period and Advanced EEG and Pediatric EEG each one, usually with approximately half of the students paying the full price and the other half receiving a bursary. During this period, we were extremely happy and grateful to welcome and acknowledge the Michael Foundation of Germany as a steady supporter of our program, providing regular bursaries to a limited number of applicants for our courses.

As shown in Table 1 during the period 2013 to 2017, a considerable number of 539 professionals entered the courses (157 the 2013 – 2014 courses, 143 the 2014 – 2015 courses, 120 the 2015 – 2016 courses and 119 the 2016 – 2017 courses). Of the 539 students, 250 were full payers (46.4%), 256 received a bursary (47.5%) and 33 got a bursary from the Michael Foundation (6.1%).

TABLE I: Funding of VIREPA Courses 2013 - 2017

Course Totals/Percentages	2013-2014 Bursary/Full Pay 77 (49%)/80 (51%)	2014-2015 Bursary/Full Pay/MF Bursary 62 (43%)/69 (48%)/12 (8%)	2015-2016 Bursary/Full Pay/MF Bursary 57 (48%)/52 (43%)/11 (9%)	2016-2017 Bursary/Full Pay/MF Bursary 60 (50%)/49 (41%)/10 (8%)
EEG Advanced		30 (15*, 2**)	30 (14*, 6**)	21 (9*, 4**)
EEG Basic	29 (16*)	30 (17*, 4**)	35 (17*, 2**)	35 (13*, 3**)
EEG Basic Jan 2014	32 (15*)	33 (13*, 1**)	31 (11*, 2**)	37 (14*, 3**)
EEG Pediatric	27 (14*)	26 (13*)	24 (10*, 1**)	26 (13*)
Medical Treatment		10 (3*, 2**)		
Genetics	9 (4*)			
Psychiatric Aspects Part 1	9 (4*)			
Psychiatric Aspects Part 2	6 (2*)			
EEG SCORE	20 (9*)			
Epilepsy & Sleep	25 (16*)	14 (8*, 3**)		

(* self-payers, ** MF bursary; MF: Michael Foundation)

For content details of VIREPA COURSES 2013 – 2017 click here (please construct the link with the attached information about the contents of the VIREPA courses.)

COMMISSION ON EDUCATION *(continued)*

For content details of VIREPA COURSES 2013-2017 please see ILAE.org

This success of the EEG courses notwithstanding, both the failure of the other courses and the worries about the work-, time- and financial burden of the by now “classical” Virepa course format prompted a discussion on how to continue.

In order to ease the financial burden to ILAE it was decided in Istanbul in 2015, that from then on, all work by the course directors, creators and tutors should be “pro bono”.

Moreover, a new task force, headed by Sam Wiebe, was created to work on new formats and educational technologies, providing relevant epilepsy education to larger audiences in less tutor-and time-intensive ways.

At the time of closure of this period, no actual new courses have been developed yet to the point of being introduced, but promising and even exciting developments are in the making, notably in the field of Imaging and EEG.

The current EEG Courses (BEEG; two courses per annual period, AEEG and PEEG) will be continued and in 2017-2018, Epilepsy and Sleep will be offered again in collaboration with the European Working Party on Epilepsy and Sleep. Other developments will depend on the outcome of the discussions within the task force.

The end of 2016 also marked the end of the active period of Verena Hészer-von Wehrs, who was the original creator of the format of the current VIREPA courses and for many years, more recently together with Priscilla Shisler, the practical coordinator of the courses. She will be dearly missed and remembered fondly by all tutors and students who were part of and/or profited from the VIREPA program during the 2013-2017 period and before.

B. Education Courses during IEC

The Education Commission, with the leadership of Walter van Emden Boas, successfully planned education courses for the 31 IEC held in Istanbul in 2015. The education courses were programmed in five series with a total of 66 teaching sessions and nearly 40 highly recognized academic speakers. The preparation of approximately 33 congress educational hours required nearly 1,100 duty hours for academic

and administrative work. Sessions were well attended and the high quality was highly appreciated by the interested audience. A similar organization is under construction for the 32 IEC in Barcelona.

C. CEA Educational activities

I. CEA core courses 2014

- EPODES-Pediatric Epilepsy Surgery (Brno, 13-17/1)
- 8th Migrating Course on Epilepsy (Dubrovnik, 5-10/10) 2015
- 6th Eilat Educational Course on Pharmacology (11-15/10)
- EPODES-Epilepsy Surgery Course (Brno, 13-17/1)

II. CEA sponsored educational activities 2014

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

2015

- 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)

COMMISSION ON EDUCATION *(continued)*

2016

- 7th Stereo-EEG Course (Venice, 12-16/2)
- 3rd International Course on Drug Resistant Epilepsies (Tagliacozzo, Italy, 8-14/5)
- 7th Caucasian Summer School (Tbilisi, Georgia, 25-27/5)
- 10th Baltic Sea Summer School (Trakai, Lithuania, 5-10/6)
- 2nd East-European Course on Epilepsy (Romania, 8-10/6)
- 3rd Dianalund Summer School on EEG (Denmark, 17-23/6)
- 4th Neuropathology Summer School (Erlangen, 31/7-4/8)
- 2nd Inflammation & Immunity workshop (Milan, 13-15/10)

III. Teaching courses at the European Congress on Epileptology (ECE)

- 11th ECE (Stockholm; 29/6-3/7/2014); the CEA awarded 50 travel bursaries to young investigators (< 45 years) who submitted good abstracts
- 12th ECE (Prague; 11-15/9/2016); the CEA awarded travel bursaries to 42 young investigators (< 45 years) who submitted good abstracts

IV. Visiting professorships

- Two Visiting Professorships (Portugal & Romania)

Online evaluation system of the courses

Together with the ILAE Education Commission, the CEA developed a web-based tool where students can give their feedback and evaluate the courses they attended. The CEA tested this evaluation system and it worked well: it provided valuable, objective information about the quality of the courses. Please see the results at: <http://www.ilae.org/Commission/CEA/documents/Results-CEA-course-evals.pdf>

D. Latin American Commission Educational Activities

The Latin American Commission with its academic branches ALADE (*Academia Latinoamericana de Epilepsia*) and LASSE (*Latin American Summer School on Epilepsy*) organized a number of activities where professors volunteer

their time. Each year, LASSE lasts 10 days with diverse types of attendees from physicians to social workers, and is held in Sao Paulo, Brazil. There are 50 students per year and each year a different topic is reviewed covering basic, clinical and social aspects. During the last ten years, more than 700 neurologists and neuroscientists coming from all Latin American countries had the opportunity of bridging knowledge on epilepsy. The planned topic for 2017 will be "Neurodevelopment and Epilepsy"; organizers received more than 300 registrations and candidate selection is hard work. Financial support for this activity is a concern. Bursaries are obtained from the government of Brazil, ILAE and pharmaceutical companies. Additional three-day courses are supported by ALADE. For instance in the past years, several were held in Cuba, Guatemala, Venezuela, Bolivia, Paraguay, El Salvador and Nicaragua covering the main topics of semiology, EEG, treatment and primary health care in epilepsy. One-year fellowships in epileptology are also available for deserving trainees in Latin America. The commission offers three bursaries of \$12,000, two for neurologists and one for a neurosurgeon. 21 persons have been trained during a six year period and three additional bursaries for 2017 are programmed. There are more than 20 applications per year. This is the sixth year of the program and every fellow has to return to his country for at least 1-2 years to work in a public or university hospital. A successful online pilot education program for primary care providers has finished its third version on December 2016. The aim was to decrease the diagnostic and therapeutic gap in epilepsy, through a virtual course, language and cost-friendly, devoted to primary care physicians in Latin America. The project was designed by the ILAE Education Commission and submitted to evaluation by ILAE. It included eight topic-specific modules of one-week duration each, including epidemiology, clinics, diagnostic procedures, drug treatment, and social and legal aspects. A 16-member Latin American teaching team developed the contents. Virtual platform and formal accreditation were obtained through international university collaboration. Repositories and discussion forums were developed. Approval required passing the final exam. Initially developed as a Spanish course, during 2016 all the platform and didactic

COMMISSION ON EDUCATION (continued)

material can be accessed either in Spanish or Portuguese, and Brazilian tutors were included in every module. Overall, 95 professionals from 15 countries registered and started the course; 77 completed all modules and approved the final examination. Approximately 20% (11-27%) felt confident about epilepsy patients' management before the course, increasing to a mean of 71% (64-84%) after the course. Financial support from ILAE for the three courses (2015-2016) was USD \$13,000, with a total revenue from registrations of USD \$5,700 (Net ILAE investment: USD \$7,300).

E. Commission on Asian and Oceanian Affairs: Educational Activities

The Asian Epilepsy Academy (ASEPA) has helped to organize the didactic teaching program of the biennial Asian and Oceanian Epilepsy Congress. However, concern exists that it was only reaching out to physicians in the richer countries that can afford to travel. Therefore, the ASEPA has also been organizing a series of 1-3 day workshops of different themes, about ten for each year, in various parts of Asia. The longer duration "Summer Schools" are also being held yearly in China and India by the China and Indian chapters. In 2016, the ASEPA with the Global Campaign Task Force, attempted the first "summer school" with the specific objective of overcoming treatment gap. The summer school attempts to reach out to the neurologists/pediatricians/internists who look after the mid-sized provincial towns. These physicians are where the rural epilepsy patients would be referred to for diagnosis and treatment. The training of these physicians may help to enhance the epilepsy care of the communities that they serve, and help to overcome the epilepsy treatment gap. The first such summer school was held in Banjarmasin, South Kalimantan, Indonesia, for the physicians from Kalimantan and nearby Sulawesi. It is proposed that this "summer school" be repeated in 2017 for the Eastern part of Indonesia. The Asian Commission has been giving two epilepsy fellowships yearly each for \$7,000 US. The ASEPA also organize an EEG certification examination which has tremendously helped raise the quality of EEG reading in Asia. The examination is in two parts, part I consists of MCQ, and part II is clinical. To date, 650 candidates have passed part I, and

250 candidates part II. The passing rate is 63% for part I and 73% for part II.

F. Commission on African Affairs

In North Africa and the Middle East, each country has a chapter. But there are limited CEMA activities other than the bi-annual Congress. There is a need to develop an annual course for neurologists, primary caregivers and nurses. This course could be attached to the sub-regional congresses. There is also a need to encourage web-based educational activities. In Sub-Saharan Africa, there are even concerted efforts and the need for improved communications in Africa is evident. There is also a need to educate the population, traditional healers and local leaders; not only physicians. South Africa offers training for a number of African physicians in adult and pediatric neurology. There are also workshops, but these are organized by pharmaceutical companies. CAA organizes the bi-annual congress that will take place in Dakar, Senegal after a very interesting congress in Cape Town, South Africa in 2015.

G. Epileptic Disorders

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

Commissioned submissions could be increased, including publications from members of the Education Commission.

- Develop didactic sections that will be self-sustained.
- Publish ILAE reports and commentaries from the Commissions
- Supplements could be published following the ALADE and ASE programs.
- Re-enforce the link between paper version and online version
- Promote the nearly 300 video sequences that are free at the website.
- Ask authors to develop two slides with their main educational message

COMMISSION ON EDUCATION *(continued)*

for each approved paper. There will also be 2-3 questions per paper.

- Add a new section on neuroimaging and neuropathology
- Include a video atlas of animal models and EEG
- Publish an editorial by the Educational Commission of the League reviewing efforts around the world.

I. Recommendations for Future Work

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

COMMISSION ON EPIDEMIOLOGY



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Charles Newton (Kenya)
Pierre-Marie Preux (France)
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David Thurman (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 ON EPIDEMIOLOGY *(continued)*

Commission Accomplishments (2013-2016)

The **Mortality Task Force** was initiated during the previous Commission term with the purpose of assessing overall mortality risks and causes of death among people with epilepsy and identifying priorities to prevent premature death in epilepsy. In late 2016, the Task Force completed its work with the submission and publication of two systematic reviews of published research, one describing epilepsy mortality in high-income countries and one in lower- and middle-income countries.^{1,2}

The **Comorbidity Task Force** commenced during the previous Commission term with the purpose of assessing the burden of psychiatric comorbidities among people with epilepsy. The Task Force is completing a systematic literature review in preparation for a manuscript report, anticipating its submission later in 2017.

The **Prevention Task Force** was conceived in 2013 to assess the need and opportunities for primary and early secondary epilepsy prevention and to recommend steps toward prevention. The Task Force has conducted a systematic review of published studies of epilepsy incidence that address preventable causes in both higher- and lower-income countries and is commencing preparation of a summary manuscript. The submission of this report of its findings and recommendations is anticipated later in 2017.

In response to the 68th World Health Assembly Resolution on the Global Burden of Epilepsy (2015), in 2016 the Commission formed a new **Global Burden Task Force** charged to develop:

- An improved region-specific assessment of the global burden of epilepsy, relying on recent published meta-analyses and systematic reviews where possible;
- An authoritative ILAE definition of 'epilepsy treatment gap';
- An assessment of the world-wide and region-specific epilepsy treatment gaps; and
- An estimate of the global cost of epilepsy.

The Commission expects the work of this Task Force to continue into the next term of the ILAE.

The **Epilepsy Registry Task Force**, which was proposed in 2013, intended to identify and promote opportunities for developing epilepsy registries. Due to limitations in funding and workload, its activities were suspended in early 2015 for the duration of this term of the Commission.

Recommendations for Future Work

The principal tasks of three Task Forces of the Commission have been—or soon will be—substantially met through the publication of their reports. The published assessments of the Mortality, Comorbidity, and Prevention Task Forces will also yield recommendations that can be promoted through other ILAE Commissions, in collaboration with WHO and other governmental and non-governmental agencies to promote research and public health interventions for epilepsy.

The Commission recommends that ILAE continue to promote public health surveillance and research in the epidemiology of epilepsy, where possible, recognizing its importance in monitoring and assessing the effectiveness of current and future prevention and healthcare programs addressing epilepsy.

¹ Levira F et al. Premature mortality of epilepsy in low- and middle-income countries: A systematic review from the Mortality Task Force of the International League Against Epilepsy. *Epilepsia* 2017, 58(1):6–16.

² Thurman DJ et al. The burden of premature mortality of epilepsy in high-income countries: A systematic review from the Mortality Task Force of the International League Against Epilepsy. *Epilepsia* 2017, 58(1):17–26.

COMMISSION ON GENETICS



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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. The number of single-gene epilepsy genetic association studies, however, is gradually dwindling over time as new approaches such as GWAS become more common. To unify the

Genetics Commission's approach to online epilepsy genetics initiatives, we plan to merge epiGAD into the Epilepsiome project in 2017.

b. ILAE Genetics Commission Blog:

To provide better outreach and communication to the professional community, the ILAE Genetics Commission has decided to maintain a blog on topics related to genes and seizures, and we have continued to use the format of the "Beyond the Ion Channel" blog that was initially developed within European initiatives surrounding epilepsy genetics. The ILAE Genetics Commission blog has slowly transformed into a knowledge base on epilepsy genes and with the support of the ILAE funding, we have reviewed gene-level information on the most relevant 30 epilepsy genes, which is updated on a regular basis.

The readership of the blog has increased significantly. As of January 2017, more than 3,000 people have subscribed to the blog and more than 600 people working in the field have signed up for the email newsletter. The visitors per month have increased from 6,000-7,000 per month to an average of 10,000 views per month. In 2016, the blog was accessed 120,000 times and the most recent gene reviews on SCN2A, SCN1A, and STXBP1 were viewed more than 5,000 times each. For the Genetics Commission, the blog has proven extremely valuable as an outreach tool to the community.

c. Epilepsiome:

The concept of the Epilepsiome comprises the extension of the genetics blogs to a comprehensive online database on epilepsy genes. Conceptually, we decided to provide gene level information in an intuitive format ("What do you need to know") for all major epilepsy genes; an effort that is maintained with the help of trained genetic counselors. As indicated above, the current gene reviews are amongst the most frequented aspects of the Epilepsiome knowledge base. In addition, both Heather Mefford and Ingo Helbig are members of the NIH-funded ClinGen consortium, an international expert panel to organize information on epilepsy-related genes. The ILAE Genetics Commission has agreed to closely collaborate with the ClinGen Initiative, providing an optimal link between the epilepsy-specific domain expertise within the Genetics

COMMISSION ON GENETICS *(continued)*

Commission and the gene review expertise of the ClinGen consortium. We expect that the emerging connection with gene review groups will contribute significantly to the sustainability of our online knowledgebase.

Initiative 2:

Assist in the creation of a centralized database of complete sequence data with variant calls paired with clinical information for as many patients as possible throughout the world, that are sequenced for epilepsy of unknown cause.

This concept, formally known as the “Epilepsy Genetics Initiative (EGI)” has now been launched as a result of planning between the NIH-sponsored “Epi4K Center Without Walls” and the Chicago-based “Citizens United for Research in Epilepsy,” and with substantial assistance from members of the Genetics Commission. See: <http://www.cureepilepsy.org/egi/index.asp>. ILAE members are encouraged to track the growth of this project and become actively involved in helping patients learn about the benefits of participation.

Initiative 3.

Continue the important work of the ILAE Consortium on Complex Epilepsies, led by Sam Berkovic.

The Consortium continues to grow in terms of both academic members and new samples with genomic data (now ~14,000 subjects). In the last 12 months, the Consortium met three times by teleconference and twice face-to-face (Prague Sept 2016; Houston Dec 2016). The major achievement was consolidation of the data on a server at the Luxembourg Centre for Systems Biomedicine. This involved substantial work by Roland Krause and the analysis committee regarding data cleaning and IRB issues. Our previous analyses involved aggregating summary statistics from contributing centers – now raw data can be meta-analyzed and this enables more sophisticated analyses, which are underway.

Our Lancet Neurology (Sept 2014; [http://www.thelancet.com/journals/laneur/article/PIIS1474-4422\(14\)70171-1/fulltext](http://www.thelancet.com/journals/laneur/article/PIIS1474-4422(14)70171-1/fulltext)) has attracted a lot of interest, including from groups working outside the epilepsy field, on conditions co-morbid

with epilepsy. Work on shared genetic markers with schizophrenia, other neuropsychiatric disorders and migraine (Brainstorm Consortium, Broad Institute; Hong Kong group – papers in submission) have utilized the Consortium public data. The Consortium has also been involved in ascertainment of cases of rash associated with anti-epileptic drugs in work led by the Dublin group (paper in submission). The Consortium has also acted as a nidus for collecting new cases for Epi25; a Consortium centered at the Broad Institute where the aim is to perform whole exome sequencing on 25,000 epilepsy cases, of which 6,000 have already been completed. Without the network and cooperative spirit engendered by the ILAE Consortium, under the umbrella of the ILAE Genetics Commission, it is unlikely that this massive collection, from Centers around the world, could have been achieved.

Initiative 4:

Improve genetic literacy among both patients and providers.

Educational Brochures: An English version of the educational brochure entitled “Epilepsy and Genetics: Things You Want to Know,” designed by Alica Goldman and other Commission members for patients and family members, is now available through the ILAE Genetics Commission website. Positive public reception of the material has prompted culturally sensitive Spanish, Arabic, and Japanese translations aimed at the Spanish speaking Latin American, Arabic, and Japanese populations (<http://www.ilae.org/Commission/genetics/>). These documents are now posted on the ILAE website and tracking of public interest in these documents has shown consistent public interest. Broad public interest in learning the essential principles of epilepsy genetics has led to a Thai translation that is under development. 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 Genetics Commission, under the leadership of Nigel Tan, started a new series on Genetic Literacy

COMMISSION ON GENETICS (continued)

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 was published in Nov 2015, the second in mid-2016. Three more papers are currently being circulated within the Commission before submission in the 1st quarter of 2017. We are encouraged by the reviewers' feedback and comments, and we anticipate this series will run through 2017 to 2018.

Initiative 5:

Facilitate networking among patients/families, clinicians and researchers for improving the care of people with known gene mutations as the cause of their epilepsy.

In the past year, the Genetic Commission has brought together representatives of a number of patient registries with the goal of creating a "global epilepsy genetics registry." The intent is that the registry will enable patients with genetically-proven epilepsy to network with others having the same form of epilepsy, and to also enable clinicians and scientists to identify patients with specific gene mutations throughout the world in order to accelerate opportunities for research. The "Global Genetic Epilepsy Registry" was launched in the fall of 2016 (see: <http://www.geneticepilepsy.com/>), a working charter has been drafted and accepted by the founding members, and the registry was highlighted at the

recent meeting of the American Epilepsy Society. Plans for the current year are to receive formal approval from the ILAE for sponsorship of the registry, and to network with foundations, family groups and clinical testing labs to publicize and extend the reach of the resource.

Recommendations for Future Work

Once again, 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; this should be facilitated with further editions of the Genetic Literacy Series. 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 and the Global Genetic Epilepsy Registry. Finally, through the work of the ILAE Consortium, we will continue to encourage and support the international collaborations that are leading to exciting advances in gene discovery.

COMMISSION ON MEDICAL THERAPIES



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COMMISSION ON NEUROBIOLOGY



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The strategic plan of the Neurobiology Commission is organized in five main initiatives implemented by *ad hoc* Task Forces. The progress of TF activities are verified and updated during yearly meetings of the Commission and teleconferences.

Update of Dissemination and Educational TF activities and continuity plan

The Commission planned activities for the 2017 ILAE Congress in Barcelona (Spain). The Neurobiology Symposium (September 3rd 2017) will be focused on **Understanding the Complexity and Networks of Epilepsies and their Associated Comorbidities**. The program includes the following lectures:

- The human brain and the search for networks and connectivity maps associated to the epilepsies and their comorbidities. Maxime Guye (France)
- Neurogenesis and gene cascade linking epilepsy to depression and autism. Steve Danzer (USA)
- Brain somatic mutation in MTOR and epileptogenesis — Hoon-Chul Kang (Republic of Korea)

- Etiology and cognitive impairment: Networks as a therapeutic target to improve outcomes. Rodney Scott (UK)
- Complexity emergence in epileptogenic networks: Clinical experimental and computational challenges and perspectives. Norberto Garcia-Cairasco (Brazil).

Other 2017 ILAE Congress sessions that highlight neurobiology include the following themes: Novel technologies; Precision medicine; Understanding the nature of seizures; Network imaging - post main session; MicroRNA; Autoimmunity and inflammation.

The **Harinarayan Young Neuroscientist Award**, first awarded during the 2015 ILAE meeting, will be funded in 2017 by the Commission for \$4,000. The Award proposal has been presented to the 2017 ILAE Congress Scientific Organizing Committee. Details on the organization of the award and on the procedures for candidates and awardees selection will be developed during the year. A text was prepared by Commission members for dissemination and to advertise the Award (Figure 1).

Harinarayan Young Neuroscientist Award

The *Harinarayan Young Neuroscientist Award of the Neurobiology Commission* is designed to encourage and reward young basic science investigators (within 10 years of completing PhD or MD training) committed to epilepsy research.

This new Award is generously supported by a donation of the Harinarayan Family. Candidate should submit and abstract to the ILAE meeting together with a paper on epilepsy research published in the last 2 years.

Two awardees are selected by the members of the Neurobiology Commission. The awardee will be invited to XIV WONOEP.

The Prize (2,000 \$) will be acknowledged during the Welcome Ceremony of ILAE Congress and will be awarded during the Neurobiology Symposium.

In 2016, two neuroscience/neurobiology meetings were sponsored by the Neurobiology Commission: The 2016 Gordon Conference in Catalonia, Spain and the Latin America Neurobiology Workshop held in Cancun, Mexico. The main topic of the Gordon Research Seminar and Conference (August 20-26, 2016; <https://www.grc.org>) was Mechanisms of Epilepsy and Neuronal Synchronization. The conference, chaired by Heinz Beck and Steve Danzer hosted 158 attendees, with a strong increase in particular amongst European Ph.D. students and post-docs. The main sub-themes

COMMISSION ON NEUROBIOLOGY *(continued)*

of the Conference were “Dynamic Epilepsy Circuits and Their Modulation” (speakers: J. Huguenard, S. Crandall, L. Ewell, Sedigh-Shervani) and “Aberrant Circuits to Impaired Function” (speakers: Y. Ben-Ari, G. Tamas, A. Becker, Y. Elgersma, C. Gross, D. Isbrandt, H. Lerche, M. Wong, C. Henneberger, N. Allen, C. Christian, N. Rouach, C. Barnes, P. Golshani, F. Mormann, U. Rutishauser, PP Lenck-Santini, A. Sirota, L. Colgin, I. Lampl, L. Menendez de la Prida, L. Mucke, J. Maguire, T. Baram, L. Cancedda, L. Lavis, J. Paz, S. Baraban, E. Krook-Magnusson). Just before the conference (from 20-21st August), the first Gordon Research Seminar for young investigators attended by 60 Ph.D. students and junior post-docs was organized by A. Omar and L. Ewell. The event will be included as a regular feature of the Conference.

The **1st Latin American Workshop on Neurobiology of Epilepsy** (main theme: Looking for new therapeutic strategies for pharmacoresistant epilepsy) organized in Cancun, Mexico, was attended by 43 scientists from five Latin American Countries. Main topics of the meeting were: Models to evaluate epilepsy and pharmacoresistance; new targets to control epilepsy, looking for the best antiepileptic treatment. Speaker and list included L Rocha, S. Orozco, A. Rosilio, L. Lorigados, J. Ortiz, J. Cavazos, E. Cavalheiro, R. Arida, A. Talevi, A. Lazarowski, P. Fagiolino, M. Vazquez N. Garcia-Cairasco and E. Perucca.

The Neurobiology Commission included in the 2017 budget proposal was a request by the International School of Neurology in Venice to support the sixth edition of the San Servolo Course on Bridging Clinical and Basic Epileptology (July 17-28, 2017).

The main project of the **Educational and Beyond Training TF** did not proceed because no complementary funding to run exchange programs for young neuroscientists from economically disadvantaged Countries was obtained.

A scheme for support/funding requests to the Neurobiology Commission has been developed and is currently utilized to select events proposed for sponsorship (see funding request form at <http://www.ilae.org/Commission/neurobio/TF-Education.cfm>).

Future plans: The **Dissemination TF** is expected to plan yearly dissemination strategies within and beyond the epilepsy research community. One of them is the Neurobiology Symposium at the ILAE and the ECE Congresses and at Regional Chapter Congresses. The symposium topic is proposed and selected within the Commission, following consultation with the SAC of the Congresses. Interactions with AES and CEA to run joint projects are well advanced and in progress. Exchanges with Neuroscience Societies such as FENS and IBRO to join forces on specific projects have been attempted.



Figure 2. 1st Latin American Workshop on Neurobiology of Epilepsy

COMMISSION ON NEUROBIOLOGY (continued)

WONOE TF activities update and continuity plan

The **WONOE TF** organized the 2013, 2015 and 2017 editions of the Workshops on Neurobiology of Epilepsy (WONOE), and the ILAE discussion forum on the pathophysiology of seizures, epilepsy and epileptogenesis, since 1987. A new WONOE format has been implemented since 2013. A main workshop theme is defined by the Commission (following Commission member proposal and selection) and five

half-day sessions on specific subthemes are organized based on the accepted abstracts. Each session starts with a 30-minute critical introduction by a key-note speaker, followed by 8-10 data-blitzes (ten min. each) and concluded by a general debate led by a panel of invited discussants. Highlights of WONOE sessions are summarized and expanded into review reports on specific sub-topics that are submitted for publication to *Epilepsia* as *WONOE appraisals*.

The image shows three sample pages of WONOE appraisals and workshop summaries. Each page has a header 'CRITICAL REVIEW AND INVITED COMMENTARY' and a small icon of an open book. The first page is titled 'WONOE appraisal: Molecular and cellular biomarkers for epilepsy' by Lorenz B. Waldner, Christof Jungjohann, Ralf Ritzmann, Christoph Bannasch, and Matthias Pohl. The second page is titled 'WONOE appraisal: Biomarkers of epilepsy-associated comorbidities' by Teresa Ramirez, Felix Y. Onat, Cheng R. Swales, David, Benjamin Depaulis, Wafar S. Saleem, and Anshu Menon. The third page is titled 'Workshop on neurobiology of epilepsy appraisal: Imaging biomarkers in epilepsy' by Brian A. van Vliet, Stefano Bendoricchio, Andrew J. Cole, Stefan Friedrich, Marilisa J. Koyak, Helmut Parvika, Mikko Ilmoniemi, Ake Pitkanen, and Paolo Fedorov.

One WONOE appraisal on *Development of epilepsy biomarkers: What we can learn from our patients*, organized by Jeff Loeb and Sergiusz Jozwiak, is under revision on *Epilepsia*.

The organization of the **2017 XIV WONOE** was discussed and planned. The workshop will take place at Mon St Benet, Barcelona, Spain, August 28th – September 1st 2017. The main theme selected by the Neurobiology Commission members is “Epilepsy as a Network Disease: From Concept to Strategy,” proposed by Rodney Scott. The theme is re-proposed as a main topic of the Neurobiology Symposium at the 2017 ILAE Congress and will be discussed during the WONOE Highlight session the first day of the Congress.

The Scientific and Organizing Committee of XIV WONOE includes Rodney Scott, Liset Menendez Da La Prida, Raman Sankar, Katja Kobow and Marco de Curtis. The main theme is further broken down into five subthemes: System Biology, Local Neural Networks (in-vitro), Local Neural Networks (in-vivo), Regional Networks (electrophysiology) and Regional Networks (imaging). Proposed XIV WONOE keynote speakers are Alicia Goldman, Liset Menendez De La Prida, Rodney Scott, Ivan Soltesz and Hal Blumenfeld. Keynote speakers will give a general introductory talk that reviews the current knowledge on the specific topic.

Participants will be instructed to coordinate a focused debate that will be preliminary to the development of a WONOE review on the specific topic. The first announcement of the 2017 XIV WONOE was published and disseminated through the NBC mailing list on September 20th 2016. The deadline for abstract submission is January 1st, 2017. Abstracts will be selected by January 31st, 2017 by WONOE TF and Organizing Committee. The final program of XIV WONOE is expected for April 1st 2017.

A WONOE dissemination slide was developed and distributed (below).

WONOE
Workshop on Neurobiology of Epilepsy

XIV Workshop on Neurobiology of Epilepsy
WONOE 2017
Mon St Benet, Barcelona, Spain
August 28th – September 1st 2017

EPILEPSY AS A NETWORK DISEASE: FROM CONCEPT TO STRATEGY

Scientific and Organizing Committee
Rod Scott, Liset Menendez Da La Prida, Raman Sankar, Katja Kobow, Marco de Curtis

WONOE XIV is a satellite event of the 32nd ILAE/IBE Congress
Abstract submission closes January 15th 2017.
Abstracts of max 300 words should be submitted as Word files to
woneep@epilepsycongress.org
Abstract submission form available at the Neurobiology Commission website
http://www.ilae.org/Commission/neurobio/events.cfm

XIV WONOE subthemes: System genetics, Local Neural Networks (in-vivo, in-vitro and in-silico), Regional Networks: electrophysiological approach, Regional networks: imaging approaches

COMMISSION ON NEUROBIOLOGY *(continued)*

The 2015 and 2017 editions of WONOE were partially funded by the *Harinarayan Family Foundation*, engaged through the commitment of WONOE TF Chair, Raman Sankar.

Translational TF activities update and continuity plan

The **Joint ILAE-AES Translational Research TF**, chaired by Jackie French, Aristeia Galanopoulou, Terry O'Brien, and Michele Simonato, developed a multifaceted project to improve the translational relevance and competence of pre-clinical research in epilepsy. The TF aims at identifying optimal methods and strategies, and to recommend developments to optimize the use of resources that can accelerate the discovery and validation of new AETs and clinically relevant biomarkers that address current gaps in epilepsy treatment, in particular drug resistant seizures, anti-epileptogenesis/disease modification and comorbidities. The TF prepared several position papers that are either accepted or under evaluation on *Epilepsia*. An update on the TASK1-4 activities and the future development for each task are detailed below.

TASK1 group (co-leaders Galanopoulou, de Curtis, Ikeda) organized in six working groups, aims at harmonizing the methodology and interpretation of video electroencephalographic (vEEG) and in-vitro electrophysiological studies used in preclinical epilepsy research. TASK1 is completing the first planned set of manuscripts on vEEG surface and depth studies on adult and immature experimental control rodents as well as on in-vitro electrophysiological studies using brain slices which will be submitted for a dedicated *Epilepsia* Supplement. The WG5 report (standards on data acquisition and software-based analysis) has been accepted for publication at *Epilepsia*. The WG4 report (methodological standards for in vitro models of seizures) is under revision for *Epilepsia*. The WG1 (in vivo video-EEG recordings in adult experimental control rodents) and WG3 (depth recordings in experimental control rodents) reports are in a final form to be submitted to *Epilepsia* and WG2 report (in vivo video-EEG recordings in immature experimental control rodents) is fast developing. An additional report in electrodes used in electrophysiological experiment is also being developed.

Future plans:

- (A) The group intends to continue with a second set of manuscripts on terminology and classification of seizures and other electrographic

abnormalities or behaviors seen in animal models of seizures and epilepsies, as well as in in vitro models of seizures. This is an important goal due to the lack of accepted terminology in animal studies that confounds the interpretation of animal studies. This effort is expected to continue through the second term of the TF, as it may require unbiased review of data to resolve areas of debate.

- (B) There is also a plan to prepare an online atlas of rodent EEGs and electrophysiological studies and make this publicly available as a reference tool. This atlas will be developed in parallel to the planned efforts to harmonize the terminology and classification of seizures in animal studies.
- (C) Furthermore, TASK1 WGs (WG4 and WG5) are working towards the development of preclinical common data elements (CDEs) for in-vitro studies in epilepsy research, in collaboration with the TASK3 EEG CDE working group.
- (D) As these goals are being developed and planned, there is also discussion on how to disseminate these products through educational programs in meetings or workshops or training courses aiming to improve the competencies of young investigators involved in translational epilepsy research.

TASK2 group (co-leaders Simonato, Brooks-Kayal, Jensen) aimed to prepare systematic reviews to evaluate animal models of seizures and epilepsies. A manuscript providing an overview of the usefulness of systematic reviews and meta-analysis for preclinical research is ready for submission. TASK2 formed a collaboration with CAMARADES group (**C**ollaborative **A**pproach to **M**eta-**A**nalysis and **R**eview of **A**nimal **D**ata from **E**xperimental **S**tudies; Drs Macleod, Howell, Sena). The first selected topic was on the “*identification and characterization of outcome measures reported in animal models of epilepsy*”. The aim of this systematic review is to define the phenotypic features of the most commonly used epilepsy models. Its protocol is currently submitted for publication to the planned *Epilepsia* supplement.

Future plans:

The vision of TASK2 is that the systematic review on outcomes will provide a broad basis for other more focused reviews. There will be an effort in training people to conduct systematic

COMMISSION ON NEUROBIOLOGY *(continued)*

reviews and meta-analyses. The experience and collaborations established so far, as well as these trained people, will facilitate the continuation of the initiative with new, focused systematic reviews. There is also a plan to create an infrastructure to collect and offer to the community of epileptologists the databases of relevant articles on epilepsy pre-clinical research and the systematic reviews and meta-analyses that will be produced.

TASK3 group (co-leaders Scharfman, French, Pitkanen) aimed at producing preclinical common data elements (CDEs) for epilepsy research studies with special focus on core, behavioral, physiology, pharmacology, EEG CDEs. NINDS has also supported this effort through the involvement of NINDS staff (current NINDS representative: Dr. Whittemore). Common data elements and CDE forms were developed, in particular for: behavior; physiology (general animal parameters); pharmacological studies; EEG; core data (strain, sex, age etc.). A final version of these forms will be soon circulated amongst NBC members and could be posted on the NBC website for evaluation/testing. The first set of preclinical CDEs was openly presented for feedback at an open forum session during the 2016 AES meeting in Houston (December 6th, 2016) and has been circulated for feedback amongst various investigators and TASK members. A general TASK3 report by the Co-Chairs is currently in preparation for submission for the *Epilepsia* supplement which presents a broad overview of preclinical epilepsy CDEs. There are also ongoing discussions as to how to liaise with other research areas that are also planning preclinical CDEs (spinal cord injury, traumatic brain injury, and stroke) through the TASK3 NINDS liaison, Vicky Whittemore.

Future plans:

- (A) TASK3 plans to finalize the preclinical CDEs within 2017 (before the end of the term) and hopefully post them as public access documents online (ILAE, AES, NINDS sites).
- (B) In the near future, there is a plan to expand them to more focus areas. For example, preclinical CDEs for in-vitro electrophysiology studies are currently planned in collaboration with

TASK1. Other CDEs (e.g., for models, imaging, neuropathology, etc.) will probably need to be the focus of new WGs in the next term of the TF.

- (C) There are discussions to plan for training activities to disseminate these CDEs to the investigators.
- (D) Explore the possibility to create software that could be easily acquired and utilized by labs to facilitate the use of CDEs. Of interest, in the open forum on preclinical CDEs in Houston, the availability of user friendly software for the use of CDEs was thought to be a significant tool to facilitate the use of CDEs in individual labs.

TASK4 group (co-leaders O'Brien, Moshé, Ikeda) aimed at creating infrastructure for large multicenter preclinical studies proposed to be a second stage of preclinical development, following single laboratory hypothesis generating studies that aim to provide a higher level pre-clinical evidence for efficacy prior to progressing to clinical trials. The trials would apply the rigor in design and study procedures that are standard in clinical Phase II/III trials, including blinding, central coordination, randomization, pre-determined endpoints, sample size calculation and external monitoring. It was envisaged that this model would be particularly applicable to potential anti-epileptogenic/disease modifying treatments. TASK4 formed a collaboration with multiPART consortium (Drs. Howell, Macleod, Sena) which conducts such studies for stroke research with the goal to extend to epilepsy studies. A template for how such studies could be undertaken and funded was published in *Epilepsia*. Utilizing the combined expertise and progress made through the TF, the first antiepileptogenesis study has been organized by several members of the TF (EpiBios4Rx) and will be funded by NINDS as a *Center Without Walls*. This will serve as a "proof-of-concept" study to test the proposed model.

TF activities will be disseminated at neuroscience and epilepsy meetings, and at ILAE-sponsored Courses and meetings. The original papers generated by the TF will be published as regular review manuscripts, marked by a special TRANSLATIONAL TF-NBC tag (to be defined). AG proposed to write periodic reports of NBC and TF activities on open-access *Epilepsia Open* journal.

COMMISSION ON NEUROBIOLOGY *(continued)*

Neurobiology Commission Continuity Plan

The projects of the ILAE Neurobiology Commission during the 2013-2017 term relied on the activities of topic-specific Task Forces focused on specific issues. The following activities represent new or consolidated developments that could be continued during the next term:

The **Dissemination TF** planned yearly dissemination strategies within and beyond the epilepsy research community. One of these is the Neurobiology Symposium at the ILAE and the ECE Congresses and at Regional Chapter Congresses. The symposium topic is proposed and selected within the Commission, following consultation with the SAC of the Congresses.

Interactions with AES and CEA to run joint projects are well advanced (see *Translational TF*) and in progress. Exchanges with Neuroscience Societies such as FENS and IBRO to join forces on specific projects have been attempted.

The **Joint ILAE-AES Translational Research TF** chaired by Aristeia Galanopoulou developed a multifaceted project to improve the translational relevance and competence of pre-clinical research in epilepsy. The TF aims at identifying optimal methods/strategies and recommend developments to optimize the use of resources that can accelerate the discovery and validation of AETs and clinically relevant biomarkers. Specifically:

- **TASK1 group** (co-leaders Galanopoulou, de Curtis, Ikeda) aimed at harmonizing the methodology and interpretation of video electroencephalographic (vEEG) and in vitro electrophysiological studies used in preclinical epilepsy research. TASK1 is completing the first planned set of manuscripts on vEEG surfaces and in-depth studies on adult and immature experimental control rodents, as well as on in-vitro electrophysiological studies using brain slices (to be submitted to *Epilepsia* for a supplement).

Future plans: The group intends to continue with a second set of manuscripts on terminology and classification of seizures and other electrographic abnormalities or behaviors seen in animals of seizures and epilepsies. This is an important goal due to the lack of accepted terminology in animal studies that confounds

the interpretation of animal studies. This effort is expected to continue through the second term of the TF, as it may require an unbiased review of data to resolve areas of debate. There is also a plan to prepare an online atlas of rodent EEGs and electrophysiological studies, and make this publicly available as a reference tool.

- **TASK2 group** (co-leaders Simonato, Brooks-Kayal, Jensen) aimed to prepare systematic reviews to evaluate animal models of seizures and epilepsies. TASK2 formed a collaboration with CAMARADES group (Collaborative Approach to Meta-Analysis and Review of Animal Data from Experimental Studies; Drs. Macleod, Howell, Sena). The first selected topic was on the “identification and characterization of outcome measures reported in animal models of epilepsy”. Its search protocol is currently being submitted for publication to the planned *Epilepsia* supplement.

Future plans: TASK2 intends to complete the systematic review on outcomes and expand to other topics.

- **TASK3 group** (co-leaders Scharfman, French, Pitkanen) aimed at producing preclinical common data elements (CDEs) for epilepsy research studies with special focus on core, behavioral, physiology, pharmacology, EEG CDEs. NINDS has also supported this effort through the involvement of NINDS staff (current NINDS representative: Dr. Whittemore). The first set of preclinical CDEs will be openly presented for feedback at an open forum session during the AES session (Houston, December 6, 2016, 11am-5pm).

Future plans: TASK3 plans to finalize the preclinical CDEs within 2017 (before the end of the term) and hopefully post them as public access documents online (ILAE, AES, NINDS sites). In the future, there is a plan to expand them to more focus areas (e.g., in-vitro electrophysiology studies, models), plan for training activities to disseminate these CDEs to the investigators, and also explore the possibility to create software that could be easily acquired and utilized by labs to facilitate the use of CDEs.

- **TASK4 group** (co-leaders O’Brien, Moshé, Ikeda) aimed at creating infrastructure for multicenter preclinical studies. TASK4 formed a

COMMISSION ON NEUROBIOLOGY *(continued)*

collaboration with multiPART consortium (Drs. Howell, Macleod, Sena) which conducts such studies for stroke research with the goal to extend to epilepsy studies. Utilizing the combined expertise and progress made through the TF, the first antiepileptogenesis study has been organized by several members of the TF and will be funded by NINDS as a Center Without Walls.

The main project of the **Educational and Beyond Training TF** did not proceed because of the failure in obtaining complementary funding to run exchange programs for young neuroscientists from economically disadvantaged countries.

A scheme for support/funding requests to the Neurobiology Commission has been developed and is currently utilized to select events proposed for sponsorship (see Funding Request Form at <http://www.ilae.org/Commission/neurobio/TF-Education.cfm>).

The **WONOE TF** organized the 2013, 2015 and 2017 editions of the Workshops on Neurobiology of Epilepsy (WONOE), since 1987 the ILAE forum to discuss new findings related to the pathophysiology of seizures, epilepsy and epileptogenesis. A new WONOE format has been implemented during the present NBC term. A main workshop theme is defined by the Commission (following Commission member proposal and selection) and five half-day sessions on specific subthemes are organized based on the accepted abstracts. Each session starts with a 30-min critical introduction by a keynote speaker, followed by 8-10 data-blitzes (ten min. each) and concluded by general debate led by a panel of invited panelists. Highlights of WONOE sessions are summarized and expanded into review reports on specific sub-topics that are submitted for publication to *Epilepsia* as WONOE appraisals.

The 2015 and 2017 editions of WONOE were partially funded by the *Harinarayan Family Foundation*, engaged through the commitment of WONOE TF Chair, Raman Sankar.

COMMISSION ON NEUROPSYCHIATRY



Kousuke Kanemoto

Chair

Kousuke Kanemoto (Japan)

Members

Mike Kerr (UK), Treasurer
Marco Mula (UK), Past Chair
Bertrand DeToffol (France)
David Dunn (USA)
Gerardo Filho (Brazil)
Andres Kanner (USA)
Sung-Pa Park (South Korea)
Markus Reuber (UK)
Jose Francisco Tellez-Zenteno (Canada), Secretary

EC liaison

Tatsuya Tanaka (Japan)

Subcommission Members

TF on Intellectual Disabilities

Mike Kerr (UK), Co-Chair
Kousuke Kanemoto (Japan), Co-Vhair
Christian Brandt (Germany)
Christine Linehan (UK)
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 Hakki 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)
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

Sung-Pa 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)
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.

COMMISSION ON NEUROPSYCHIATRY *(continued)*

Mission

The mission of the Commission is to ensure that health professionals, as well as patients and their care providers, have:

1. Educational and research resources essential for understanding, diagnosing, and treating various psychiatric manifestations in patients with epilepsy.
2. Have the ability to reduce prejudice, as epilepsy patients with psychiatric co-morbidities are easily exposed to a double prejudice that can affect medical personnel involved in their treatment

Commission Activities from July 2013 through October 2017

Face-to-face meetings and symposia

1) Annual meeting of Neuropsychiatric Committee (2013)

7th December 2013 (Washington, Renaissance Hotel). The first meeting of the Neuropsychiatric Committee [Attendees: Kousuke Kanemoto (Japan), Mike Kerr (UK), Anders M Kanner (USA), Jose Francisco Tellez-Zenteno (USA), Sung-Pa Park (South Korea), Markus Reuber (UK), David Dunn (USA), Curt LaFrance (USA)] One additional member (Gerardo Filho) sent a presentation, which was shared with the attendees.

2) Psychosis TF small meeting (2013)

8th December 2013 (Washington, Renaissance Hotel). Psychosis task force small meeting [Attendees: Robert Cuba (Czek), Kousuke Kanemoto (Japan)]

3) PNES TF meeting and closed symposium (2014)

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

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

4) Surgery TF small meeting (2014)

30th September 2014 (Tokyo, Keio Plaza Hotel). Surgery task force small meeting [Attendees: Mayu Fujikawa (Japan), Kousuke Kanemoto (Japan), Sarah Wilson (Australia)]

5) Epilepsy, behavior and intellectual disability: A time for change. A joint symposium of the ILAE and the Japan Epilepsy Society (2014)

1st October 2014 (Tokyo, Keio Plaza Hotel). Christine Linehan (Ireland), Mike Kerr (UK), Kenji Sugai (Japan), Christian Brandt (Germany), Sara Wilson (Australia), Kousuke Kanemoto (Japan), Jun Kawasaki (Japan), Hirano Keiji & Yukai Tadokoro (Japan), Jo Wilmshurst (South Africa)]

6) Annual meeting of Neuropsychiatric committee (2014)

6th December 2014 (Everett room, located at the Seattle Sheraton Hotel, Seattle, USA). The second meeting of the Neuropsychiatric Committee [Attendees: Kousuke Kanemoto (Japan), Mike Kerr (UK), Markus Reuber (UK), Sung-Pa Park (South Korea), Gerardo Filho (Brazil), Dunn David (USA), José F. Téllez Zenteno (Canada), Mayu Fujikawa (Japan)].

7) Neuropsychiatric committee small meeting (2015)

6th September 2015 (Hilton Istanbul Bosphorus, Istanbul, Turkey). Attendees [Kousuke Kanemoto (Japan), Park Sung-Pa (South Korea), Mike Kerr (UK), Markus Reuber (UK)]

8) 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) (2015)

29th October 2015 (Nagasaki Sinbun-Bunka Hall, Nagasaki, Japan). 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), Kousuke Kanemoto (Japan),

COMMISSION ON NEUROPSYCHIATRY *(continued)*

Hiroko Ikeda (Japan), Sung-Pa Park (South Korea), Go Taniguchi (Japan), Dong Zhou (China), Ravi Paul (Zambia), David Gigineishvili (Georgia), Mike Kerr (UK).

9) Annual meeting of Neuropsychiatric Committee (2015)

7th December 2015 (Marriott Philadelphia Downtown 403, Philadelphia, 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)]

10) Depression in patients with epilepsy: How could neurologists, psychiatrists and neurosurgeons co-work and how much do Asian colleagues acknowledge it? (2016)

9-10th October 2016 (Aichi Medical University, Nagakute, Japan). Speakers [Kousuke Kanemoto (Japan), Andres M. Kanner (USA), Alice Yu (Taiwan), Masumi Ito (Japan), Sung-Pa Park (South Korea), Aileen MacGonigal (France), Riki Matsumoto (Japan), Go Taniguchi (Japan),

Takuji Nishida (Japan), Oh-Young Kwon (South Korea), Zhou Dong (China), Yotin Chinvarun (Thailand)]

11) Psychiatric issues of surgery for refractory epilepsy. A multidisciplinary approach (2016)

22nd October 2016 (São Paulo, Brazil) Speakers [Gerardo Filho (Brazil), Jose Tellez-Zenteno (Canada), Elza Marcia Yacubian (Brazil), Andres M. Kanner (USA); Mayu Fujiwara (Japan); Kousuke Kanemoto (Japan); Marco Mula (UK), Markus Reuber (UK), Steffi Koechstecker (Germany)]

Task force report

- Intellectual Disability TF: Mike Kerr, Christine Linehan, Christian Brandt, Kousuke Kanemoto, Jun Kawasaki, Kenji Sugai, Yukari Tadokoro, Vicente Villanueva, Jo Wilmshurst and Sarah Wilson. Behavioral disorder in people with an intellectual disability and epilepsy: A report of the Intellectual Disability Task Force of the Neuropsychiatric Commission of ILAE. *Epilepsia* Open 2016;1:102-111
- PNES TF symposium report: Kousuke Kanemoto (being submitted)

- PNES TF survey report: Markus Reuber (completed and waiting for approval of Executive Committee)
- Education TF report: Marco Mula (completed and waiting for approval of Executive Committee)
- Psychosis TF report: Kousuke Kanemoto (completed and waiting for approval of Executive Committee)
- Depression TF report: being prepared for approval
- Surgery TF report: being prepared for approval

Task force accomplishments, initiatives in progress from 2013 to 2016 and recommendations for the next task force

A) Task force on Intellectual Disability (chaired by Mike Kerr).

The term of the neuropsychiatry commission has been fruitful, reviewing issues pertinent to the care of people with epilepsy who have an intellectual disability. The task force has supported the publication of the White Paper on the care of people with an intellectual disability and epilepsy (A2-1).

With the support of Professor Kanemoto and Aichi University, the task force held a landmark symposium during the Japanese chapter of the ILAE meeting in Tokyo. The theme was chosen to address a key concern of patients, families and health professionals: the interaction between epilepsy and behaviour in this population. The multinational and multiprofessional meeting was a great success (A1). Following this, the task force produced and published a report on behavioural disorders in people with intellectual disability and epilepsy (A2-2). The speech delivered by Kenji Hirano, Vice-President of the Japanese branch of IBE and a father of a 26 year old daughter with Dravet syndrome, symbolized this fruitful symposium, which strongly supports the need to pay attention to this group of patients (A2-3).

Whilst the task force has made important inroads, the needs of this population remain underserved and lacking in priority. We hope the future leadership of the ILAE will support greater recognition and inclusion of the needs of people with an intellectual disability across the spectrum of ILAE activities and global reach.

COMMISSION ON NEUROPSYCHIATRY *(continued)*

Pending initiatives

Transition from child care to adult care. This topic was suggested to be picked up intensively in the discussion among TF members but not realized. Because this includes a variety of challenges inclusive of simple miscommunication between adult care and child care, lack of appropriate institutes, and lack of systemic transfer of medical information, extensive examinations and discussions will be required.

Supplementary Data

1) Meetings

Tokyo symposium

The symposium, *“Epilepsy, behavior and intellectual disability: A time for change. An international ILAE conference”*, was held in Tokyo (Keio Plaza Hotel Tokyo) on October 1st, 2014, in association with the annual meeting of the Japan Epilepsy Society (October 1st to 3rd, 2014). The purpose of the meeting was to discuss key areas of need, and solutions to these, to reduce the burden of psychological and behavioural problems, especially in adult people with an intellectual disability and epilepsy. The program was as follows:

10:00-10:05 Opening remarks.

Kousuke Kanemoto (Japan)

Session I (10:05-12:25) Christian Linehan & Jo Wilmshurst (Chairs)

10:05-10:40 The burden of disease as a public health perspective: Epidemiology-measurement of impact. Christine Linehan (Ireland)

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

11:15-11:50 Understanding behavior and mental health: The impact of causation. Kenji Sugai (Japan)

11:50-12:25 Autism, behaviour and epilepsy: challenges in adolescence. Jo Wilmshurst (South Africa)

SessionII (13:15-15:00) Kousuke Kanemoto & Sara Wilson (Chairs)

13:15-13:50 Understanding behavior and mental health: The impact of AEDS. Christian Brandt (Germany)

13:50-14:25 Treatment: Psychological approaches. Sara Wilson (Australia)

14:25-15:00 Treatment: Role of medication. Kousuke Kanemoto (Japan)

SessionII (15:20-17:30) Mike Kerr & Christian Brandt (Chairs)

15:20-15:50 Characteristic behavioral problems in patients with intellectual disability, with and without epilepsy. Jun Kawasaki (Japan)

15:50-16:20 Social change: Policy and family burden in UK and Ireland. Christine Linehan (Ireland)

16:20-16:50 Social change: Policy and family burden in Japan. Hirano Keiji & Yukai Tadokoro (Japan)

16:50-17:30 Overall discussion and future direction of the task force

17:30-17:35 Closing remarks by Mike Kerr (UK)

2) Publications

1) Kerr M, Linehan C, Thompson R, Mula M, Gil-Nagal A, Zuberi SM & Glynn M. (2014) A White Paper on the medical and social needs of people with epilepsy and intellectual disability: The Task Force on Intellectual Disabilities and Epilepsy of the International League Against Epilepsy. *Epilepsia* 2014;55:1902-6

2) Kerr M, Linehan C, Brandt C, Kanemoto K, Kawasaki J, Sugai K, Tadokoro Y, Villanueva V, Wilmshurst J, Wilson S. Behavioral disorder in people with an intellectual disability and epilepsy: A report of the Intellectual Disability Task Force of the Neuropsychiatric Commission of ILAE. *Epilepsia Open* 2016;1:102-111

3) Hirano Y. Improving health care and welfare services for individuals with epilepsy and intellectual disabilities focusing on transition from child care to adult care: A father of a daughter with Dravet syndrome speaks out. *Epilepsy & Seizure* 2016;8:14-20

B) Task force on Psychogenic Non-Epileptic Seizure (chaired by Markus Reuber)
The PNES Task Force decided to focus on the topic of “PNES around the world” at the beginning of this committee. The ultimate goal

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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, TF 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 (B1-1). 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 (B1-2). Data analysis and preparation of a report are completed. The reports have been submitted to the Executive Committee and are waiting for approval (B2-1, B2-2).

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

Pending initiative

- Wider dissemination of the task force findings (hopefully at a symposium at the European Congress of Epilepsy in Vienna, 2018)
- Application for reconstitution of an ILAE PNES task force during the next presidential term, focusing on an internationally accepted

labeling and definition of PNES to facilitate future service planning and research.

- Prof. Adrien Grass proposed to conduct a survey on “induction protocols for PNES”. The purpose of this survey is to explore the possibility of generating international consensus on the use of suggestive seizure induction in the diagnosis of PNES. This is approved as a task of PNES TF and is now in progress.

Supplementary Data

1) Meetings

1-1) Stockholm meeting

The purpose of the meeting was to promote awareness of PNES around the world. A cross-cultural PNES study that compares diagnosis and treatment approaches is planned, because PNES may vary according to different social and cultural backgrounds. The program was as follows.

11:00-11:15: Welcome and Introductions – Kousuke Kanemoto, Markus Reuber & Mike Kerr

11:15-11:45: PNES, PNES services & research in Brazil – Kette Valente

11:45-12:15: PNES, PNES services & research in the USA - Curt LaFrance

12:15-12:45: PNES, PNES services & research in Chile – Alejandro De Marinis

13:00-13:30: PNES, PNES services & research in Iran – Aliakbar Asadi Pooya

13:30-14:00: PNES, PNES services & research in Georgia – David Gigineishvili

14:00-14:30: PNES, PNES services & research in Zambia – Ravi Paul

15:30-16:00: PNES, PNES services & research in Japan – Kousuke Kanemoto

16:00-16:30: PNES, PNES services & research in South Africa – Chrisma Pretorius

16:30-17:00: PNES surveys conducted in the UK: A possible model for surveys elsewhere? – Markus Reuber

17:15-19:00: Design of research plans for global PNES Task Force.

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1-1) Nagasaki symposium

A symposium entitled as "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)" was held in Nagasaki, October 29, 2015 along with the JES annual meeting (October 30-31). It aims to disseminate recent insights into the diagnosis, causes and best treatment of this common differential diagnosis of epilepsy. The discussion of the manifestations and treatment of PNES around the world, and treatment gaps for patients with PNES in different countries, allowed attendees to consider how to optimize their own services for patients with this potentially disabling disorder. The time schedule for the meeting was as follows:

10:00-10:05 Opening remarks. Kousuke Kanemoto (Japan)

10:05-10:10 Welcome speech by the guest of honor. Yozo Miyake (Japan, President of Aichi Medical University)

10:10 -10:40 Possible, probable, and definite PNES. How strict should the diagnosis for the optimal therapeutic intervention. William Curt LaFrance, Jr. (U.S.A)

10:40-11:10 What are PNES? A biopsychosocial model of the disorder. Markus Reuber (UK)

11:10-11:40 Difficult and easy cases of PNES. Video demonstration. Kazutaka Jin (Japan)

12:40-13:10 Epidemiology of PNES. Rod Duncan (NZ)

13:10-13:40 Health economical problem of PNES. Tomohiro Oshima and Yukari Tadokoro (Japan)

13:40-14:10 PNES in patients with intellectual disability. Etsushi Kato, Haruko Goji and Kousuke Kanemoto (Japan)

14:10-14:40 PNES in children. Hiroko Ikeda (Japan)

14:40-15:10 Psychiatric problems in PNES. Sung-Pa Park (South Korea)

15:30-15:50 PNES in Japan. Go Taniguchi (Japan)

15:50-16:10 PNES in China. Dong Zhou (China)

16:10-16:30 PNES in Zambia. Ravi Paul (Zambia)

16:30-16:50 Preliminary results of PNES task force survey in Georgia. David Gigineishvili (Georgia)

16:50-17:30 PNES: The next ten years Mike Kerr (UK)

17:30-17:35 Closing remarks. Markus Reuber (UK)

1) Publications

2-1) Kanemoto K, LaFrance WC, Duncan R, Gigineishvili D, Park SP, Tadokoro Y, Ikeda H, Paul R, Zhou D, Taniguchi G, Kerr M, Oshima T, Jin K, Reuber M. PNES around the world: Where we are now and how we can close diagnosis and treatment gaps. An ILAE PNES Task Force report (submitted)

2-2) Hingray C, El-Hage W, Duncan R, Gigineishvili D, Kanemoto K, LaFrance WC, de Marinis A, Pretorius C, Wiseman H, Téllez Zenteno JF, Reuber M. Access to diagnostic and therapeutic facilities for psychogenic non-epileptic seizures: An international survey by the ILAE PNES Task Force (completed and waiting for approval from the ILAE executive committee)

Education TF (chaired by Marco Mula)

The aim of the task force was to stimulate and support education on neuropsychiatric aspects of epilepsy formulating proposals to address educational needs of epileptologists. The task force focused on three main projects: (1) development and implementation of the VIREPA course on "Psychiatric Aspects"; (2) promoting education of psychiatric comorbidities in regional and local epilepsy meetings; (3) formulating proposals on the basis of educational needs of epileptologists and other healthcare professionals working with people with epilepsy.

(1) VIREPA course on "Psychiatric aspects of epilepsy"

The VIREPA course on psychiatric aspects of epilepsy has run for two consecutive years. It has received excellent feedback from students in terms of importance, quality of the training and impact on clinical practice. However, the number of applicants remained too low (ten or less each year) to make it sustainable. For this reason, in addition to the current global financial situation, the course was suspended in 2015.

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(2) Promoting psychiatric comorbidities in regional and local epilepsy meetings:

Task force members have been very active in promoting psychiatric comorbidities in regional and local meetings and educational events. Some examples are the 9th Latin America Summer School on Epilepsy organised by Esper Cavalheiro (Brazil) and held in Sao Paulo. The course was dedicated to comorbidities in epilepsy, with several sessions dedicated to psychiatric comorbidities in children and adults with epilepsy. Andres M Kanner gave several lectures on common psychiatric comorbidities in epilepsy and on the role of the neurologist after the diagnosis of PNES. Alla Guekht (Russia) organised two workshops in 2015; one in Russia and one in Kazakhstan; and special attention was given to somatic and psychiatric comorbidities of epilepsy.

(3) Survey on Educational Needs:

The task force designed a quantitative questionnaire to survey the self-perceived confidence of child and adult epileptologists and psychiatrists in managing major psychiatric comorbidities of epilepsy to identify critical areas of improvement from a list of skills that are usually considered necessary for effective management of these conditions, and the preferred educational format for improving these skills. Confidence and usefulness scores suggest that respondents would most value education and training in the management of specific clinical scenarios. Child neurologists identified major Axis I disorders like mood and anxiety disorders, while adult neurologists identified attention deficit hyperactivity disorder, intellectual disabilities and autistic spectrum disorder as key areas. Both adult and child neurologists identified screening skills as the priority. Results of the survey will be published as a Task Force Report (C1).

Supplementary Data

Publications

Mula M, Cavalheiro E, Guekht A, Kanner AM, Lee HW, Ozkara C, Thomson A, Wilson SJ. Educational needs of epileptologists about psychiatric comorbidities of the epilepsies: A

descriptive quantitative survey (completed and waiting for approval from the ILAE Executive Committee)

Psychosis TF (chaired by Bertrand DeToffol)

Psychosis TF planned three initiatives: 1) to examine the awareness gap between patients and treating doctors about psychotic experiences in patients with epilepsy; 2) to propose a positional paper about pharmacological intervention against psychosis in patients with epilepsy by international experts on this issue; 3) to conduct a survey of the current knowledge and awareness of psychosis in patients among neurologists and psychiatrists in different countries. The first initiative, planned and conducted together with the ex-Chair of this TF, Robert Cuba (Czech Republic), emphasized that this gap really existed (D1-1). The second initiative is now completed and is waiting for approval from the Executive Committee (D1-2).

Pending initiative

The data for the third initiative was already accumulated in three countries (France, Brazil, and Japan) and will be soon in the process of analysis.

Supplements

1) Publications

1-1) 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
1-2) Kanemoto K, Trimble M, Hesdorffer DC, Taylor L, Sachdev P, Clancy M, Adachi N, Bragatti JA, Mula M, Bertrand DeToffol. Pharmacotherapy in patients with epilepsy and psychosis. An ILAE PNES task force report. (completed and waiting for approval from the Executive Committee)

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Depression TF (chaired by Sung-Pa Park)

The Depression TF aimed first to heighten awareness of depression in patients with epilepsy and promote accessibility to assessment of depressive states globally. In order to achieve this goal, the screening instrument developed to identify major depressive episodes in patients with epilepsy, the Neurologic Depressive Disorder Inventory in Epilepsy (NDDIE) underwent validation and translation in various countries, which resulted in French, Chinese, and Danish versions (2-1, 2-2, 2-3). Translation and validation of the screening instrument used to identify generalized anxiety disorder, the Generalized Anxiety Disorder-7 (GAD-7), was also recommended and promoted (2-4, 2-5, 2-6).

Secondly, to promote the accessibility of the validated NDDI-E and GAD-7 in individual countries, Dr. Park and Dr. McGonigal encouraged the French and Korean Epilepsy Society to publish it on the banner of their websites.

Thirdly, Dr. Mula and Dr. McGonigal validated the use of the NDDI-E as a suicidality-screening instrument. They found that item 4 of the NDDI-E has shown to be an excellent suicidality screening instrument (2-7).

Fourthly, Dr. McGonigal developed the ultra-short versions of the NDDI-E (NDDIE-2) and the GAD-7 (GAD-SI). She concluded that these screening tools are likely to facilitate screening of MDE and GAD (E2-8).

Fifthly, Dr. Park examined the impact of depression in epilepsy patients. He found that depression was closely associated with poor quality of life (E2-9), suicidality (2-10), aggression (2-11), adverse effects of antiepileptic drugs (E2-12), fatigue (E2-13), perceived stress (2-14), and irritability (2-15).

Sixthly, the Depression TF tried to shed light on the problem of interdisciplinary co-work between psychiatrists and neurologists (or neurosurgeon), which is indispensable for efficient and seamless therapeutic intervention to patients with depression and epilepsy. For this purpose, an international meeting approved by ILAE and supported by Aichi Medical University's Science Promoting Program was planned and successfully held at Nagakute, Japan on October 9-10, 2016 (E1). In this symposium, Asian epilepsy experts who were interested in this topic were also invited, which heightened awareness on this issue were heightened (E1).

Seventh, Dr. Kanemoto, as a member of the Depression TF, visited Korea at August, 2016, as a consultant by the invitation of the Korean Epilepsy Society about the issue of a wrong regulation related to covering public insurance after only 60 days when

whole clinicians except psychiatrists prescribe SSRI and SNRI in Korea. He participated in a public hearing of the Korean National Assembly together with Dr. Park and spoke on the appropriate use of antidepressants in epilepsy patients. Through their efforts, there was the effectuation of the revised enforcement regulations since January 2017. Four major neurological disorders such as epilepsy, stroke, dementia, and Parkinson's disease became exceptional for 60 days of restriction.

Pending initiative

Task force reports as a fruit of Nagakute symposium are now being prepared for approval of the Executive Committee.

Supplementary data

1) Meetings

Nagakute symposium

A symposium titled "Depression in patients with epilepsy: How could neurologists, psychiatrists and neurosurgeons co-work and how much do Asian colleagues acknowledge it?" was held on October 9-10th, 2016 at lecture room 302, Aichi Medical University, Nagakute-shi, Aichi, Japan. The schedule was as follows:

9th Sunday

14:00-14:05 Opening remarks. Kousuke Kanemoto (Japan)

14:05-14:10 Welcome speech by the guest of honor. Yozo Miyake (Japan, President of Aichi Medical University)

14:10-14:35 Epidemiology of comorbid depression in patients with epilepsy (including bidirectional relationship between epilepsy and depression). Andres Miguel Kanner (USA)

14:35-15:00 Do antidepressant drugs worsen or improve epileptic seizures? Pros and cons debate. Andres Miguel Kanner (USA) and Kousuke Kanemoto (Japan)

15:00-15:25 Depression in epilepsy: Why should neurologists care? Alice Yu (Taiwan)

15:35-16:00 Neurobiological aspects of mood disorders: Do they explain the high comorbidity of depression and epilepsy? Masumi Ito (Japan)

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16:00-16:25 Can psychiatric adverse events of AEDs be anticipated at the time of the initial evaluation of the seizure disorder? Kousuke Kanemoto (Japan)

16:25-16:50 What is the impact of depression on seizure, psychosocial issues and behavioral problems? Sung-Pa Park (South Korea)

16:50-17:15 Can neurologists identify patients with depressive and anxiety disorders in their outpatient clinic? Aileen McGonigal (France)

17:15-17:40 When should patients be referred to psychiatrists? Riki Matsumoto (Japan)

17:40-18:05 Depression in patients with epilepsy in Japan. Go Taniguchi (Japan)

10th Monday

9:00-9:20 Depression before and after epilepsy surgery. Takuji Nishida (Japan)

9:20-9:40 Depression in patients with epilepsy in Korea. Oh-Young Kwon (South Korea)

9:40-10:00 Depression in patients with epilepsy in China. Zhou Dong (China)

10:00-10:20 Depression in patients with epilepsy in Thailand. Yotin Chinvarun (Thailand)

10:20-10:40 Depression in patients with epilepsy in Taiwan. Alice Yu (Taiwan)

10:40-11:10 Overall discussion. Sung-Pa Park (South Korea)

11:10-11:20 Closing remarks. Kousuke Kanemoto (Japan)

1) Publications

2-1) Micoulaud-Franchi JA, Barkate G, Trébuchon-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.

2-2) 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.

2-3) 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; 25:33:41-5.

2-4) Seo JG, Cho YW, Lee SJ, Lee JJ, Kim JE, Moon HJ, Park SP. Predictors of quality of life and their interrelations in Korean people with epilepsy: A MEPSY study. *Seizure* 2014; 23:762-8.

2-5) Tong X, An D, McGonigal A, Park SP, Zhou D. Validation of the Generalized Anxiety Disorder-7 (GAD-7) among Chinese people with epilepsy. *Epilepsy Res* 2016; 120:31-6.

2-6) Micoulaud-Franchi JA, Lagarde S, Barkate G, Dufournet B, Besancon C, Trébuchon-Da Fonseca A, Gavaret M, Bartolomei F, Bonini F, McGonigal A. Rapid detection of generalized anxiety disorder and major depression in epilepsy: Validation of the GAD-7 as a complementary tool to the NDDI-E in a French sample. *Epilepsy Behav* 2016; 57:211-6.

2-7) Mula M, McGonigal A, Micoulaud-Franchi JA, May TW, Labudda K, Brandt C. Validation of rapid suicidality screening in epilepsy using the NDDIE. *Epilepsia* 2016; 57:949-55.

2-8) Micoulaud-Franchi JA, Bartolomei F, McGonigal A. Ultra-short screening instruments for major depressive episode and generalized anxiety disorder in epilepsy: The NDDIE-2 and the GAD-SI. *J Affect Disord* 2016; 210:237-40.

2-9) Lee SJ, Kim JE, Seo JG, Cho YW, Lee JJ, Moon HJ, Park SP. Predictors of quality of life and their interrelations in Korean people with epilepsy: A MEPSY study. *Seizure* 2014; 23:762-8.

2-10) Seo JG, Lee JJ, Cho YW, Lee SJ, Kim JE, Moon HJ, Park SP. Suicidality and its risk factors in Korean people with epilepsy: A MEPSY Study. *J Clin Neurol* 2015; 11:32-41.

2-11) Seo JG, Kim JM, Park SP. Perceived stigma is a critical factor for interictal aggression in people with epilepsy. *Seizure* 2015; 26:26-31.

2-12) Kim SK, Park SP, Kwon OY. Impact of depression and anxiety on adverse event profiles in Korean people with epilepsy. *Epilepsy Behav* 2015; 46:185-91.

2-13) Kwon OY, Park SP. Interictal fatigue and its predictors in epilepsy patients: A case-control study. *Seizure* 2016; 34:48-53.

2-14) Moon HJ, Seo JG, Park SP. Perceived stress and its predictors in people with epilepsy. *Epilepsy Behav* 2016; 62:47-52.

2-15) Kwon OY, Park SP. Interictal irritability and associated factors in epilepsy patients. *Seizure* 2016; 42:38-43.

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Surgery TF (chaired by Gerardo Filho)

The Epilepsy Surgery task force aimed to explore the topic of how to evaluate the psychiatric risks of patients with epilepsy who undergo epilepsy surgery, especially in tertiary epilepsy centers. The ultimate goal of this project to allow more patients with epilepsy to gain access to an appropriate evaluation, diagnostic and treatment services with appropriate training and equipment. The international meeting in São Paulo (F1) was planned and successfully performed in order to help this goal to be achieved, which was educational for its contributors and is expected to produce outcomes which are helpful to them and colleagues around the world. The purpose of the meeting was to discuss key areas of need, and solutions to these, to reduce the burden of the psychiatric issues associated with epilepsy surgery on individuals and society. We anticipate that this collaboration will result in several publications and presentations by the task force as a whole, but probably also publications of aspects of this work by individual contributors.

Pending initiative

Task force reports as a result of São Paulo symposium are now being prepared for approval for the Executive Committee. A systemic review about presurgical assessment tools entitled, "Neuropsychiatric Assessment in Surgical Evaluation in Epilepsy: Systematic Review" is being prepared by Mayu Fujikawa.

Supplementary data

1) Meetings

São Paulo symposium

A symposium entitled "Psychiatric issues of surgery for refractory epilepsy: A multidisciplinary approach" was held on October 22, 2016 at Maksoud Plaza Hotel in Alameda Campinas, 150 - Bela Vista, São Paulo/SP, Brazil.

The schedule was as follows:

9:00-9:10: Welcome and introductions - Kousuke Kanemoto & Gerardo M. de Araujo Filho

9:10-9:35: Epidemiology of psychiatric disorders in epilepsy: What do we know? – Dr. Tellez-Zenteno

9:35-10:00: Refractory epilepsy syndromes and their surgical indication: The importance of the psychiatric status – Prof. Elza Marcia Yacubian

10:00-10:25: Psychiatric disorders in pre-surgical candidates and their possible impact on seizure outcome – Andreas Miguel Kanner

11:05-11:30: What are the most common obstacles that preclude epilepsy centers from performing pre-and post-surgical psychiatric evaluations and treatment to surgical candidates? Andreas Muguel Kanner

11:30-11:55: What is the prevalence and impact of post-surgical de novo PD? – Kousuke Kanemoto

13:30-15:30: What would be the minimal requirements for pre-surgical psychiatric evaluations in epilepsy centers? - Psychiatric issues of epilepsy surgery Task Force

Depression: Andreas Miguel Kanner (20')

Anxiety disorders: Marco Mula (20')

Psychosis: Kousuke Kanemoto (20')

PNES: Markus Reuber (20')

Discussion (20')

15:30-16:00: Coffee break

16:00-18:30: Models of psychiatric care in epilepsy centers from different countries: Strengths and barriers

Report of the survey to the surgical centers: Steffi Koechstecker (20')

USA: Andreas Miguel Kanner (15')

Canada: Jose Tellez-Zenteno (15')

Japan: Mayu Fujikawa & Kousuke Kanemoto (15')

Brazil: Gerardo M. de Araujo Filho (15')

UK: Markus Reuber (15')

Discussion (40')

18:30: Final remarks - Kousuke Kanemoto & Gerardo M. de Araujo Filho

TF on Child Neuropsychiatry (chaired by David Dunn)

Two initiatives have been tackled. The first, special issues about child neuropsychiatry in patients with epilepsy edited by Frank Besag, was published and has attracted intensive attention. This initiative was originally discussed, planned, and conducted in the

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previous Neuropsychiatric Committee chaired by Marco Mula and Andreas Miguel Kanner, and realized thanks for the perseverant efforts of Frank Besag. The second initiative is a collaborative effort to make a consensus paper on ADHD in children with epilepsy.

Pending initiative

A consensus paper on ADHD in children with epilepsy is being developed by the Pediatric Comorbidities task force headed by Stephane Auvin and Jo Wilmshurst. Eleven questions will be addressed. David Dunn will be the representative from the child neuropsychiatry task force.

Supplementary data

1) Publications

Epileptic Disorders, Volume 18, Supplement 1, May 2016.

1. Besag F, Aldenkamp A, Caplan R, Dunn DW, Gobbi G, Sillanpää M. Preface. S1
2. Sillanpää M, Besag F, Aldenkamp A, Caplan R, Dunn DW, Gobbi G. Psychiatric and Behavioural Disorders in Children with Epilepsy (ILAE Task Force Report): Epidemiology of psychiatric/behavioural disorder in children with epilepsy. S2
3. Besag F, Gobbi G, Caplan R, Sillanpää M, Aldenkamp A, Dunn DW. Psychiatric and Behavioural Disorders in Children with Epilepsy (ILAE Task Force Report): Epilepsy and ADHD. S8
4. Besag F, Aldenkamp A, Caplan R, Dunn DW, Gobbi G, Sillanpää M. Psychiatric and Behavioural Disorders in Children with Epilepsy (ILAE Task Force Report): Epilepsy and Autism. S16
5. Dunn DW, Besag F, Caplan R, Aldenkamp A, Gobbi G, Sillanpää M. Psychiatric and Behavioural Disorders in Children with Epilepsy (ILAE Task Force Report): Anxiety, depression and childhood epilepsy. S24
6. Besag F, Caplan R, Aldenkamp A, Dunn DW, Gobbi G, Sillanpää M. Psychiatric and Behavioural Disorders in Children with Epilepsy (ILAE Task Force Report): Epilepsy and psychosis in children and teenagers. S31
7. Besag F, Gobbi G, Aldenkamp A, Caplan R, Dunn DW, Sillanpää M. Psychiatric and Behavioural Disorders in Children with Epilepsy (ILAE Task Force Report): Behavioural and psychiatric disorders associated with epilepsy syndromes. S37
8. Besag F, Gobbi G, Aldenkamp A, Caplan R, Dunn DW, Sillanpää M. Psychiatric and Behavioural Disorders in Children with Epilepsy (ILAE Task Force Report): Subtle behavioural and cognitive manifestations of epilepsy. S49
9. Aldenkamp A, Besag F, Gobbi G, Caplan R, Dunn DW, Sillanpää M. Psychiatric and Behavioural Disorders in Children with Epilepsy (ILAE Task Force Report): Adverse cognitive and behavioural effects of antiepileptic drugs. S55
10. Besag F, Caplan R, Aldenkamp A, Dunn DW, Gobbi G, Sillanpää M. Psychiatric and Behavioural Disorders in Children with Epilepsy (ILAE Task Force Report): Behavioural effects of epilepsy surgery. S68
11. Besag F, Aldenkamp A, Caplan R, Dunn DW, Gobbi G, Sillanpää M. Psychiatric and Behavioural Disorders in Children with Epilepsy (ILAE Task Force Report): When should pharmacotherapy for psychiatric/behavioural disorders in children with epilepsy be prescribed? S77

COMMISSION ON PEDIATRICS



Jo Wilmshurst

Chair

Jo Wilmshurst (South Africa)

Members

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Marilisa Montovani Guerreiro (Brazil)
Makiko Osawa (Japan)
Vinayan [K. P.] Puthenivill (India)
Pauline Samia (Kenya)

EC Liaison

Helen Cross (UK)

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

Stéphane Auvin, Hans Hartmann, Amy Brooks-Kayal, Roberto Tuchman, Pauline Samia, Vinayan KP Puthenivill, Marilisa Guerreiro, Jo Wilmshurst, Patrick Van Bogaert, Elaine Wirrell, Kette Valente, Mike Kerr, Donald Kirsty, Bruce Hermann, Marylou Smith, Makiko Osawa, Lionel Carmant, Rochelle Caplan, Madison Berl, David Dun

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

Jo Wilmshurst (South Africa), Chair

Emilio Perucca, Alla Guekht, Mary Secco

Pediatric Epilepsy Surgery Task Force

William D Gaillard (USA) Chair

Task Force for the Update of the Neonatal Recommendations: Ronit Pressler (UK) and Hans Hartmann (Germany) Co-Chairs

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 the government for essential aspects of the guidelines/recommendations and so on.

Commission activities from July 2015 through June 2016

The Commission on Pediatrics has held one formal and two informal productive meetings over the period July 2015 - June 2016 at major international meetings where a concentration of the commission members were present. This has allowed focused planning and discussion with the various task forces which the commission is working on over the current cycle.

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Task Force Adaptation of the Guidelines

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. The PET courses that occurred this year in two regions (South India and South Africa) with support from ILAE were successful. There are now some 500 health workers and physicians who have completed PET1 in India.

Under the auspices of the South African national child neurology organization (PANDA SA), the first African Paediatric Epilepsy Training course was run in Cape Town, in February 2016. This is in-line with the BPNA's policy to roll out the courses on an international level. The Cape Town course ran over three days with the first day consisting of the start-up course, whereby the future African faculty were taken through the curriculum by the BPNA course providers, all of whom were international experts. The next day was a focused "train-the-trainer" course. This equipped the African faculty with the skills to teach the course. Day three the African faculty ran two parallel identical courses to local South African delegates. 88 delegates completed the course and an African faculty of 36 was established. This faculty is from across ten African countries inclusive of South Africa, Zimbabwe, Kenya, Uganda, Tanzania, Nigeria, Ghana, Malawi, Sudan, and Sierra Leone. The aim being that courses will occur several times a year in different settings to reach as wide a group as possible. The next PET1 meetings are scheduled to be in November 2016 in Johannesburg, April 2017 Kisumu, Kenya and November 2017, Durban.

The creation of an international faculty with the BPNA is hoped for, as well as translating the course into Portuguese and Spanish, which is being explored to open access for the course to health practitioners in South America. The cooperation between ILAE and BPNA on PET courses should be further developed with a special emphasis to include further regions, and also to ensure quality assurance and to develop outcome measures for the impact of these courses. Such outcome measures will be extremely helpful in promoting pediatric epilepsy training and reducing

knowledge and treatment gaps. This task force is collaborating with the Education Commission and has recruited members to join the projects.

Following the San Servolo School in June 2015, the prize winning presentation project, focused on the Galle district in Sri Lanka, was expanded with the aim to assess incidence of epilepsy in children, and awareness and knowledge in this region. This is being further pursued by Dr. Gemunu Hewawitharana with the support of Commission members Hans Hartmann and Vinayan Puthenivill.

Task Force for Comorbidities in Pediatric Epilepsy.

Chair Stéphane Auvin (France)

The aim of this task force is to develop a "user friendly text" that documents the known data, identifies what is not known and highlights red flags where interventions are needed. The TF has focused on pediatric epilepsy and ADHD. A working group devised key study questions. Small sub-committees have been tasked with producing evidence-based assessments on these key questions. The final format of the report will be a consensus document which will aim to assist the clinician in practice and also to raise awareness of this co-morbidity risk in children with epilepsy. The final text is planned to provide an approachable, clear, simple recommendation and to consist of tables, flow diagrams and "red flag" messages; i.e. to be of use by 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 final text is due for completion in 2017.

The TF coordinated a satellite workshop immediately prior to the IEC 2015 in Istanbul. With the help of the Turkish Child Neurology group, especially Dilek Yalınzoğlu, presentations and discussion on the topic of epilepsy and co-morbidities in children were addressed. There was no registration charge for the meeting, and attendance was excellent, with some 60 health practitioners participating.

The neuropsychiatry group have 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. This report was published as a Special Report in *Epilepsia Open*, (Kerr et al Behavioral disorder in people with an intellectual disability and epilepsy: A report of the Intellectual Disability Task Force of the Neuropsychiatric Commission of ILAE. 1(3-4):102-111, 2016.)

COMMISSION ON PEDIATRICS *(continued)*

Pediatric Epilepsy Surgery Task Force.

William D. Gaillard (USA), Chair

The Epilepsy Surgery task force is working on four projects: eloquent cortex, neuropsychology, training, changes in pediatric epilepsy surgery 2004-2014, and has begun a fifth, establishing criteria for pediatric epilepsy surgery centers. The task force met at the ILAE meeting in Istanbul and American Epilepsy Society Meeting. The task force pediatric neuropsychology sub-commission, led by Dr. Madison M. Berl, completed their survey of pediatric neuropsychology presurgical evaluation practices. This survey was conducted in conjunction with a subcommittee of the neuropsychology sub-commission of the Commission on Diagnostics. The manuscript is pending revisions at Epileptic Disorders. Drs. Susan Koh and Guido Rubboli led 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. Such data would be very helpful for petitioning for resources and training in resource-limited economies. The data is being placed in draft form for publication. Dr. Prasanna Jayakar completed the surgical approach survey; the manuscript is drafted and due for submission for peer review. Dr. A Simon Harvey is leading a project to understand changes in epilepsy surgery practice, in-patient selection, diagnostic testing, and surgical techniques that have occurred over the past ten years based on comparing epilepsy surgery data from 2004 and 2014. Data has been collected from 18 of the original sites from the 2004 survey. A satellite meeting at Istanbul, supported by the task force (and the Pediatric Commission), convened to present and discuss results of the four above projects.

Dr Arthur Cukiert's report to the task force on the neurosurgical survey on pediatric neurosurgical techniques and practice was published in *Epilepsia*: Cukiert A, Rydenhag B, Harkness W, Cross JH, Gaillard WD. Technological aspects of pediatric epilepsy surgery: Findings from a web-based multicentre survey. *Epilepsia* 2016 Feb; 57(2):194-200. PMID: 26749250. The next step will be to address the question of the level of expertise needed for centres to be recognized as competent for epilepsy surgery in children. The initial planning meeting was held at the International Child Neurology Congress in Amsterdam. Future plans are completing the two unfinished projects: the survey on changes in pediatric

epilepsy surgery populations and practice conducted by Dr. Harvey, and the efforts to define criteria for pediatric epilepsy surgery centers.

The task force update of the neonatal seizure recommendations.

Hans Hartmann (Germany), Chair

Ronit Pressler (UK), (Neonatal Seizure Classification task force)

In order to update the 2011 WHO/ILAE/IBE guidelines on Neonatal Seizures and make it more widely known, the task force has started a process with the intent to update the guidelines in collaboration with the neonatal task force of the Commission on Classification and Terminology. This should be published in *Epilepsia*. The list of members of this task force, aimed to represent ILAE and WHO, was finalized in 2016.

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

COMMISSION ON PEDIATRICS *(continued)*

The Pediatric Advocacy task force has formed a working group with additional members from the IBE and the Advocacy TF to address how the above resolution relates to children with epilepsy and what must be in place to ensure it is effective. The draft of this report is underway and should be completed in 2017.

Accomplishments (2014-2015)

Accomplishments over this time period include facilitating the successful implementation PET courses in two major regions and the establishment of an international faculty. This has strengthened the collaboration between the ILAE and the BPNA. The Co-morbidities task force has successfully identified key study questions and collated sufficient data to permit analysis, and now writing the report. In collaboration with the Neuropsychiatry Commission, a paper was published in *Epilepsia Open*. The pediatric epilepsy surgery TF have published one paper in *Epilepsia*, have another in press in *Epileptic Disorders*, are in the process of writing up another project and collating data on the fourth. The Neonatal Seizures Recommendations TF has formulated their working group and are developing their study questions. The Advocacy TF is in the process of completing the report on the topic of the rights of the child to access consistent and reliable AEDs.

Recommendations for Future Work

Whilst papers have already been published on different aspects of pediatric epilepsy surgery as well as a recommendation on infantile seizures, ongoing updates of these activities will still be required. A consensus statement on co-morbidities related to ADHD and epilepsy will be completed in 2017 and using a similar template it is envisioned that other key topics could be addressed in the next term, such as anxiety and epilepsy. Co-operation between ILAE and BPNA was established to promote pediatric epilepsy training (PET), running highly successful courses in Africa and India. The current Commission proposes to continue work in the following area during the next term: In the field of pediatric epilepsy surgery, a focus of future commission work should be on developing criteria for the level of services/expertise in pediatric epilepsy surgery centers. Work on this has been initiated by the current task force, and preliminary results shall be discussed during a workshop on occasion of the IEC 2017. The adaptation of guidelines is ongoing work. In July 2016, the Pediatrics Commission, in collaboration with the Classifications and Terminology Commission (Neonatal Taskforce), has initiated a guideline development group in order to update the 2011 WHO/ILAE/IBE neonatal seizure guidelines, endorsed by ILAE's Executive Committee. The group aims to complete literature review and evidence profiles in 2017. The draft should be ready for ILAE and external review in 2018.

COMMISSION ON SURGICAL THERAPEUTICS



Bertil Rydenhag

Chair

Bertil Rydenhag (Sweden)

Members

Christine Bulteau (France)
Pavel Kršek (Czech Republic)
Guoming Luan (China)
Kristina Malmgren (Sweden), Secretary
Andrew McEvoy (UK)
Michael Sperling (USA), Treasurer
Bernhard Steinhoff (Germany)
Mario Allonso Vanegas (Mexico)
Serge Vuilliemoz (Switzerland)
Sanford Hsu
Taisuke Otsuki

EC Liason:

Tatsuya Tanaka (Japan)

Aims

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

Mission

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

Full Day Commission meetings held

- AES in Washington the 5th of December 2013
- 11th ECE in Stockholm the 29th of June 2014
- 31st IEC in Istanbul the 9th of September 2015
- 12th ECE in Prague the 11th of September 2016
- AES in Houston the 1st of December 2016

Educational Initiatives

The Commission on Surgical Therapies has the important task to support educational activities re: epilepsy surgery. There are an increasing number of courses in the field of epilepsy surgery. There are epilepsy surgery courses with a focus on a special investigational technique (e.g. the SEEG courses in

Europe) or courses supported by the ILAE with a focus on investigations and research related to epilepsy surgery (e.g. the San Servolo course 2016). There is also one comprehensive course cycle with a strong patient perspective aimed at conveying all the issues related to epilepsy surgery in both adults and children: the EPODES course cycle (developed within the frame of the European Program of the Development of Epilepsy Surgery) which consists of one basic and two advanced courses, and is held in Brno, Czech Republic. This course cycle was initiated as a European initiative but has received an increasing number of applications from extra-European countries and has grown during our term due to economic support from the Surgical Therapies Commission. It has developed into an international course where also extra-European participants can receive bursaries. Participants include adult neurologists, neuropediatricians, clinical neurophysiologists and also an increasing number of neurosurgeons. The start of support from the Surgical Commission was for the EPODES 2015 course. Since then, number of extra-European applications and it has been possible to provide many of these applicants with travel bursaries, which for many of them is a prerequisite for their participation.

The Surgical Commission has also economically supported the neuropathological courses organised by Ingmar Blümcke from the Diagnostics commission, and Bertil Rydenhag has been invited as speaker to this course in October 2016.

The San Servolo course 2016 was also supported economically in the budget from the Surgical Commission.

Organization of meetings, the technical epilepsy surgery meetings 2014 and 2016

Pre-operative selection, work-up and surgical outcome of pediatric patients with refractory epilepsy are frequently discussed in many local and international meetings, but a main forum was missing for epilepsy surgeons to discuss technical strategies, advantages and disadvantages of different surgical approaches and up-to-date technology. This issue was raised and discussed in 2012 at the ILAE Paediatric Epilepsy Task Force, which later led to an internet-based survey among paediatric epilepsy surgeons regarding surgical techniques that was published as a special report in *Epilepsia*. This work led to the joint initiative between the Paediatric Epilepsy Task force and the Surgical Commission to arrange specific technical meetings.

COMMISSION ON SURGICAL THERAPEUTICS *(continued)*

The first such meeting was held in Gothenburg the 4th – 5th of July 2014 as a post ECE activity, and focused on paediatric epilepsy surgery techniques. The meeting was very successful. It was attended by about 80 paediatric epilepsy surgeons; much positive feedback was given. This led to the organization of a second technical meeting, this time for both adult and pediatric epilepsy surgery, in Prague the 16th-17th of September 2016. This meeting was attended by about 80 epilepsy surgeons.

The positive reactions from the first meeting led to the plan to publish meeting proceedings. These were accepted by *Epilepsia* and are now in press. The different sections of the meeting are represented by chapters authored by the presenters at the meeting.

There are several requests for a third meeting as a satellite meeting to the next ECE in Vienna 2018. Plans for such a meeting have been initiated, and contacts have been taken with local epilepsy surgeons to be able to organise such a meeting.

Contribution to 12th ECE in Prague September 2016

The Surgical Commission had proposed a session for this congress entitled the “Risk/Benefit Stratification for Epilepsy Surgery”. The comprehensive topic reflected the view of the Commission to avoid simplification of the outcomes of epilepsy surgery. This was accepted as a teaching session with three speakers, all from the Commission, 13th of September 07.30-09.00. Pavel Kršek chaired and Andreas Schulze-Bohage co-chaired.

- “Efficacy and prognostic factors on surgical procedures”, Serge Vuillemoz
- “Medical and psychosocial risks of surgical procedures”, Kristina Malmgren
- “Risk stratification: Risk/benefit ratio and hierarchy of procedures”, Michael Sperling

Publications

Papers published in collaboration with other commissions

With the Diagnostics Commission:

Blumcke I, Aronica E, Miyata H, et al. International recommendation for a comprehensive neuropathologic workup of epilepsy surgery brain tissue: A consensus Task Force report from the ILAE Commission on Diagnostic Methods. *Epilepsia* 2016;57:348-358.

With the Task Force for pediatric epilepsy surgery

Cukiert A, Rydenhag B, Harkness W, et al. Technical aspects of pediatric epilepsy surgery: Report of a multicenter, multinational web-based survey by the ILAE Task Force on Pediatric Epilepsy Surgery. *Epilepsia* 2016;57:194-200.

Manuscript in collaboration with the Task Force for pediatric epilepsy surgery

Madison MB, Smith ML, Bulteau C. ILAE Survey of Neuropsychology Practice in Pediatric Epilepsy Surgery Evaluation. 2016; Submitted to *Epileptic Disorders* on behalf of the Task Force for Pediatric Epilepsy Surgery for the ILAE Commissions of Pediatrics and Surgical Therapies

Ongoing work with publications that will probably be submitted within term:

Recommendations on the reporting of outcomes of epilepsy surgery. Work led by Pavel Kršek and Kristina Malmgren. Most of the sections are in place, but will be edited by Kristina Malmgren and Pavel Kršek. This is planned as a didactic paper and the aim is to provide recommendations concerning outcome reporting (not guidelines).

Ongoing work with publications that will probably be submitted as part of a continuation

Stratification of risks vs benefits for surgical procedures. Originally a suggestion by Mike Sperling, parts of it have been presented at a teaching session in Prague. The continuation of the full educational paper will however probably be part of the continuity plan for a coming commission

Surgical strategies with focus on limited resources. Ongoing work led by Andrew McEvoy, who has also invited Mario Alonso for this work.

Ongoing projects in collaboration with the E-Pilepsy consortium:

Systematic review of EEG and MEG source imaging Serge Vuillemoz Serge represents the Surgical Therapies Commission. Work ongoing

Systematic review of neuromodulation Serge Vuillemoz Serge has taken on to represent the Surgical Therapies Commission. Work ongoing.

Critical review on neuromodulation and epilepsy. Mario Alonso is working on a critical review on the benefits and risks of neuromodulation which was endorsed at the Istanbul meeting to be a Commission task. Discussion about the relation with the systematic review, a decision that they can be complementary. Plan to try to submit it to *Epilepsia* as a Commission report.

COMMISSION ON SURGICAL THERAPEUTICS *(continued)*

Collaborations

As is evident from the above the Surgical commission has had an active collaboration with the Commission on Diagnostics and the Pediatric Task Force on Epilepsy Surgery. This work is ongoing. We have also had close connections and collaboration with the EU-funded E-Pilepsy consortium.

Economy

The main part of the budget for the Surgical Commission has been used to support educational initiatives on epilepsy surgery.

In short, for 2014 we had approval for \$3,500 for the technical meeting in Gothenburg, but since this meeting was finally covered by external sources the \$3,500 was reallocated to EPODES 2015: see below. The INES course was supported by \$10,000 and there was \$3,000 for VIREPA bursaries.

2015, there was support of EPODES 2015 in Brno of \$3,500 and in the budget \$5,000 for support of INES.

2016 there was a total support of Epodes 2016 in Brno of \$24,000, \$5,000 for the San Servolo course and \$3,000 for educational programs.

2017 Epodes has been supported by \$12,000.

Continuity plan for a coming Commission on Surgical Therapies

The Surgical Therapies Commission has, during its term focused on education, collaboration and safety:

Education

Education is of paramount importance for the Commission. There are epilepsy surgery courses with a focus on a special investigational technique (e.g., the SEEG courses in Europe) or courses supported by the ILAE with a focus on investigations and research related to epilepsy surgery (e.g., the San Servolo course 2016) but there is only one comprehensive course cycle with a strong patient perspective aiming at conveying the philosophy of epilepsy surgery both in adults and children: the EPODES course cycle in Brno, Czech Republic. This course cycle was initiated as a European initiative but has grown during our term due to economic support from the Surgical Therapies

Commission and developed into an international course where also extra-European participants can receive bursaries. The course has had, since this change an increasing number of participants from extra-European countries, most of whom need bursaries in order to be able to participate. For the upcoming course in January 2017 there are applicants from Asia, Latin America and Africa. We have also seen an increasing interest in the EPODES course cycle from other epilepsy professionals other than neurologists and neuropediatricians, importantly there has been an increasing number of neurosurgeons interested in the comprehensive aspects of epilepsy surgery: In 2013 there were 5; In 2016 there were 16.

Fellowships make it possible for younger colleagues to gain gaining experience by education in experienced centers. With the evolving techniques it is also increasingly feasible to have internet consultations and discussions; especially for establishing new centers, this kind of support is of paramount importance. It would therefore be useful if the Surgical Commission could take the responsibility for a knowledge base on centers which can give such support and to provide information for new centers.

Outcomes of epilepsy surgery are most often reported as observational studies. While further randomised controlled studies are warranted, it is also important to improve the quality of the observational studies. The Surgical Commission has therefore undertaken the task to write an educational paper with suggestions on how to document and report outcomes.

Continuity plan for education and training

- Sustainability in the support of comprehensive epilepsy surgery educational activities such as the EPODES course cycle
- Continued support of related educational activities such as the neuropathological courses –INES– led by Ingmar Blümcke
- Suggestion that the Surgical Commission could survey and keep updates on epilepsy surgery centres in order to be a liaison for new centres that wish to send fellows and who could contact the Surgical Commission for information
- Continued work on giving support to epilepsy surgery centres on the reporting of outcomes

COMMISSION ON SURGICAL THERAPEUTICS *(continued)*

Collaboration

The technical epilepsy surgery meetings which were initiated originally from the Pediatric Epilepsy Task Force of 2012, then planned and organised in collaboration with the Surgical Commission, represent a completely new and important initiative. Epilepsy surgeons have been able to have a forum for in-depth discussions, especially considering the important focus on resection planning in order to reduce the risk for expected or unexpected adverse events. Two such meetings have been held, the first one in Gothenburg 2014 and the second in Prague 2016, where there was also more focus on the usefulness of future techniques.

The response from all participants has been very positive, the possibility for epilepsy surgeons to meet in an informal setting and discuss and learn from each other also with much focus on safe techniques to minimise possible unexpected adverse effects has been much appreciated.

The synopsis of the main presentations from the 2014 Gothenburg meeting will soon appear as a separate supplement in *Epilepsia*. Guest editors are Arthur Cukiert from the pediatric epilepsy task force and Bertil Rydenhag representing the Surgical Commission.

The collaboration with the Commission on Diagnostic Methods has led to joining forces in educational activities as well as Commission reports. The same goes for the ongoing collaboration with the pediatric surgery task force.

Continuity plan for collaboration

- Support and cooperation with paediatrics regarding a continuation of the epilepsy surgery technical meeting series, next time in relation to the next EEC in Vienna 2018.
- Continued and extended collaboration with the Commission on Diagnostic Methods and with the pediatric surgery task force.

Safety

There is an increasing focus on safety issues in relation to epilepsy surgery: this includes surveillance in the EMU, precautions to reduce complications, as well as expected adverse events. The Commission has reviewed and endorsed a suggested new protocol for surgical and neurological complications related both to invasive procedures and to therapeutic surgery. This protocol will now be used in a pilot study to ensure

feasibility and collect more comments on practical issues as well as content. This will be followed by further methodological work in order to provide the epilepsy surgery community with a comprehensive complication scale.

The issue of expected adverse events is complicated by the fact that there is no consensus on what is an acceptable expected adverse event. An educational paper regarding these aspects in children is underway within the pediatric surgery task force, and Bertil Rydenhag has had the possibility to give his view and suggestions on this paper.

Continuity plan for safety

- Continued focus on safety issues related both to safety in the EMU with 24/7 surveillance and to all presurgical investigations and all surgical procedures. This should continue to be done together with the pediatric surgery task force, and it is therefore an advantage if some key persons, as today, are members of both the Surgical (commission and the pediatric surgery task force.)
- Epilepsy surgery carries a risk for other adverse effects other than surgical/neurological complications, e.g. cognitive. There is no clear cut-off between the cognitive impairments which are considered to be expected and those which are unexpected either in occurrence or in degree, and which may hence be considered complications. It would be valuable to try to identify such a cut-off in order to search for predictors of cognitive complications. This work needs to be planned in collaboration with the task force for neuropsychology.



Chapters

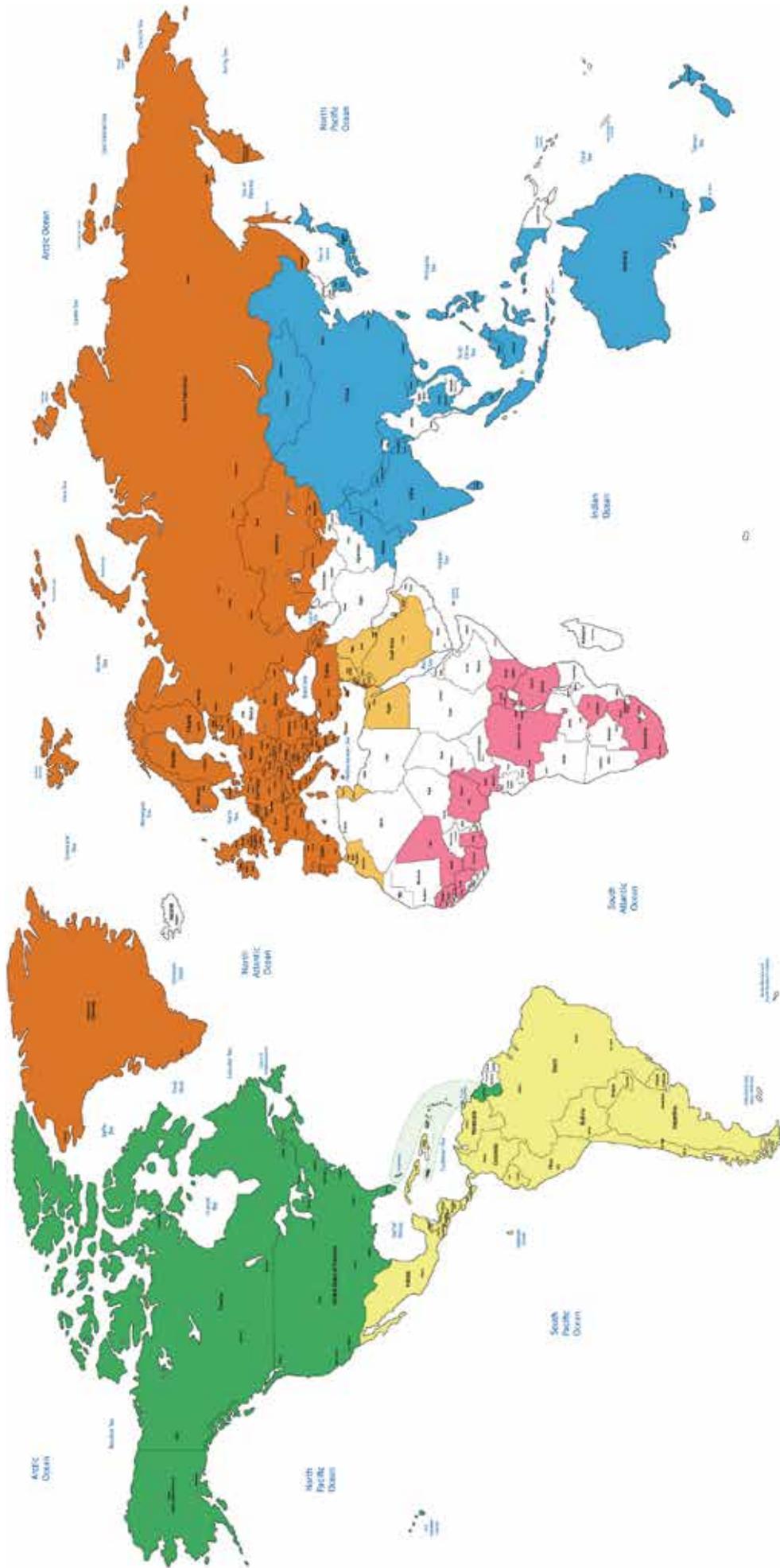
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Uzbekistan
Venezuela
Vietnam
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*Antigua, Bahamas, Barbados, Guyana, Jamaica, Martinique, St. Kitts, St. Lucia, Trinidad and Tobago, US Virgin Islands



- Commission on North American Affairs
- Commission on Latin American Affairs
- Commission on European Affairs
- Commission on African Affairs
- Commission on Eastern Mediterranean Affairs
- Commission on Asia and the Pacific



CHAPTER REPORTS

ALBANIAN LEAGUE AGAINST EPILEPSY

Publications

Meeting

Summary of Activities in 2015/16 2015

- Epilepsy Day with the very distinguished participation of Professor Raad Shakir, President of the World Federation of Neurology, and Professor Antonio Federico, Chair of Scientific Committee of European Academy of Neurology.
- Every six months a meeting with patients and their families.
- Two talks on epilepsy in local media.
- September 2015, active participation at the IEC Istanbul.
- October 2015, meeting of the Albanian Chapter.

2016

- Epilepsy Day, February 8, 2016, is celebrated at the Mother Teresa Hospital, gathering some patients, physicians and nurses at the meeting room of the service of Neurology.
- September 2016, participation of some Albanian chapter's member to the ECE Prague.
- October 27, 2016, annual organizative meeting of Albanian chapter.
- Albanian Congress of Neurology, 2-3 December 2016, a special interest session was held on epilepsy. There were different speakers and some posters on epilepsy diagnosis and treatment.

ARGENTINA: LACE- LIGA ARGENTINA CONTRA LA EPILEPSIA

Meeting

22-23 September 2016

Summary of Activities in 2015 and 2016

- We worked with the National Health Ministry to improve the diagnosis and treatment of epilepsy in the poorest states of our extensive country.
- We organized meetings with epileptologists in different regions in order to discuss patients and to learn the last definitions of epilepsy.

Summary of Activities in Relation to Global Campaign in 2015 and 2016

We worked with colleagues to approve the National Law of epilepsy in all the country – On November 2015 the National Health Ministry named epilepsy as a prevalent illness so we have access to a lot of national programs.

Educational Activities

Every September we have The Week of Epilepsy so throughout the country we give meetings to patients and their families We have a special site in the web for patients and also for colleagues.

Future Plans

We continuing working with the National Health Ministry in order to have more AEDs available for public patients. In June we have our next meeting for epileptologists in Mendoza. We want to work with other surgery centres from our region and we have our next National Epileptic Congress in October.

Officer Election Date

November 2017

Report by

Dr. Santiago Galicchio-President of LACE

AZERBAIJAN LEAGUE AGAINST EPILEPSY

Publications

19 articles were published in 2015-2016 on topics related to epilepsy.

Meeting

Scientific-Practical Conferences

Summary of Activities in 2015 and 2016

Catamenial epilepsy, and epilepsy in pregnant women have been studied. Study of epidemiology of epilepsy in different regions of Azerbaijan continues. Participation at the schools and Congress on Epileptology.

Educational Activities

School on Epilepsy for patients with epilepsy and their relatives.

Future Plans

Continuation of a study of epidemiology of epilepsy in different regions of Azerbaijan; study of etiological factors of epilepsy (epilepsy after stroke, traumatic epilepsy, epilepsy in neuroinfection, brain tumour-related epilepsy).

Officer Election Date

June 2017

Report by

Magalov Sh.I., Melikova Sh.Y.



CHAPTER REPORTS

BULGARIAN SOCIETY AGAINST EPILEPSY

Summary of Activities in 2015 and 2016

- Participation by all epilepsy-related lectures (one full day) at the Bulgarian Conference of Child Neurology, October 21-23, 2016, Sofia
- BSAE invited lecturers for epilepsy topics (from Romania, Serbia, Greece)

Educational Activities

- Application for the 2017 East-European Course on Epilepsy
- Creation of a webpage of the BSAE and posting of several epilepsy-related articles for the general audience (patients, GPs)

Future Plans

- 3rd East-European Course on Epilepsy, CEA-ILAE endorsed
- July 5-7th, 2017, Borovets resort, Bulgaria

Officer Election Date

27th November 2015

Report by

Petia Dimova (President of BSAE)

CAMEROON LEAGUE AGAINST EPILEPSY

Meeting

May 25, 2016

Summary of Activities in 2015 and 2016

May 25, 2016: Symposium on the diagnosis and management of epilepsy for medical students and nurses. General Assembly on May 25, 2016 in Douala (Conference room of the Gyneco-Obstetrics and Pediatric Hospital of Douala):

1. Admission of new members:
 - 1) Dr. Mbonda Chimi Paul (Neurologist, Yaounde General Hospital)
 - 2) Dr. Kamthuong Mbonda Laura Neurologist
 - 3) Dr. Enyama Dominique: Neuropediatrician, Gynecological Obstetrics and Pediatric Hospital of Douala
 - 4) Dr. Kenmegne Caroline: Neurologist, Douala General Hospital
 - 5) Dr. Eyoum Christian: Psychiatrist, Laquintinie Hospital of Douala
 - 6) Dr. Motouom Fotso Aline: Neurologist, Laquintinie Hospital of Douala

7) Dr. Nambou Hervé: Neurologist, Laquintinie Hospital of Douala

8) Dr. Nkouonkack Cyrille: Neurologist, Regional Hospital of Buéa)

9) Dr. Kedy Koum: Pediatrician, Gynecological-Obstetric and Pediatric Hospital of Douala)

2. Celebration of the World Epilepsy Day (13/02/2016): Activities postponed due to the late defection of the main sponsor of the event.
3. Strengthening of our collaboration with the Ministry of Public Health: As part of the strengthening of the implementation of the activities of the Strategic Plan for the Control of Non-communicable Chronic Diseases, a framework agreement was signed on October 20, 2015 between the Cameroonian Ministry of Public Health (MINSANTE), SANOFI-AVENTIS and OCEAC for the sensitization and management of epilepsy in seven health districts (Bafia, Ndikinimeki, Ntui, Sa'a, Ebebda, Monatélé and rural Ngaoundéré). The Cameroon League Against Epilepsy was appointed by the Minister of Public Health as the technical partner of the project. In this context, we have contributed to these activities: From 30th May to June 2nd, 2016 in Ebolowa (Cameroon): Seminar on the development or updating of training modules on screening, care and prevention of epilepsy for general practitioners, paramedics and the community in the 7 Targeted Health Districts. From June 29 to July 1st, 2016 in Mbalmayo (Cameroon): Seminar on the development of simplified algorithms for the management of epilepsy by general practitioners and nurses. October 19, 2016 in Mbalmayo (Cameroon): Seminar workshop for the validation of training and awareness tools on epilepsy. From November 15 to 18, 2016 in Obala (Cameroon): workshop on the training of trainers on the management of epilepsy in the seven pilot health districts of the centre region and rural Ngaoundere area.

Future Plans

Organization of the 4th African Epilepsy Congress

Officer Election in 2017

Organization of World Epilepsy Day

Report by

Pr Callixte Kuate Tegueu Secretary General



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CANADIAN LEAGUE AGAINST EPILEPSY

Publications

CLAE Connections – our league newsletter – of which five were published in 2015 and 2016. This newsletter highlights our CLAE rising stars, innovative programs and services (clinical, research or advocacy), major publications from our members, information on epilepsy related meetings, success stories in major grant competitions, etc.

Educational Meeting

Our biennial meeting was held in Quebec City, Quebec from October 14-16, 2016.

Summary of Activities in 2015 and 2016

Our biennial meeting was a great success (see below under educational activities). We also had our CLAE Connections (our newsletter) – five issues. We funded two epilepsy fellowships and awarded our usual non-trainee/allied health awards for best publications (fellow award, grad student or medical student award, resident award, and allied health student award).

Our new Board:

President: Dr. Jorge Burneo

Secretary: Dr. Mary Lou Smith

Treasurer: Dr. David A Steven

Junior representative: Dr. Kristin Ikeda

CPEN representative: Dr. Kathy Speechley

President-Elect: Dr. Dang Nguyen

Summary of Activities in Relation to ILAE

Dr. Samuel Wiebe, former CLAE President is now the President Elect of the ILAE. Dr. Nathalie Jette chairs the ILAE guidelines task force, ILAE stigma task force, and the ILAE global burden of epilepsy task force (This latter one with Dr. Arturo Carpio from Ecuador).

Educational Meeting

Our biennial meeting was held in Quebec City, during the month of October 2016, and was a major success. The number of attendees was higher than in previous meetings. Topics covered included: psychogenic non-epileptic events, role of marijuana in the treatment of epilepsy, newer imaging techniques, statistics for the epileptologist, newer EEG techniques, trauma-related epilepsy, cognition and epilepsy, epilepsy surgery failures, genetics and why seizures start and stop. The CLAE was very pleased to have our IBE affiliate, the Canadian Epilepsy Alliance, chair a plenary session on the current and past shortage of antiepileptic drugs, and the initiatives led by the CLAE in conjunction with Health Canada to ameliorate this problem. Furthermore, the work to improve epilepsy care in the

Province of Ontario has been highlighted by *Epigraph*. This initiative, led by Dr. O. Carter Snead III, has allowed the expansion of dedicated epilepsy beds in the Province, as well as the creation of different guidelines in the assessment, management, and other issues related to epilepsy care. This model serves as an example on how to improve epilepsy care in a large scale, health system with universal access.

Activities in Conjunction with Local IBE Affiliate

The CLAE is committed to working with community based epilepsy organizations. To that end, we have developed strong ties to the Canadian Epilepsy Alliance, a full member organization of the International Bureau for Epilepsy. As such, the CLAE welcomed the CEA in the planning of our 2016 Biennial meeting.

Future Plans

The new President, Jorge G Burneo, has proposed the following activities in the next two years:

1. Expansion on the number of committees, particularly the creation of one on global health
2. Improvement of advertisement through social media of all CLAE activities
3. Increase with other NARC chapters, particularly with the Epilepsy Society of the Caribbean
4. Improvement on obtaining funding from private donors and private institutions
5. Increased the number of epilepsy-related educational activities within Canada

Officer Election Date

October 2018

Report by

Dr. Jorge G Burneo, President Canadian League Against Epilepsy

CHILE: SOCIETY OF EPILEPTOLOGY OF CHILE

Publications

Chilean Journal of Epilepsy

The Chilean Journal of Epilepsy is the official publication of our Society. Dr. Perla David features as its main editor; Dr. Ledia Troncoso and Dr. Marcelo Devilat are her co-editors. During 2015 and 2016, the 15th and 16th volume of this Journal were released. This year (2017) we shall release three new chapters as part of the 17th volume. Among the published material, we can mention: original papers, case reports, reviews and updates. Our current official ISSN



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number is 0719-5397. This is the product of the hard work and dedication of the Journal staff, especially due to the efforts of Dr. David. The magazine is also available online on its own website www.revistachilenadeepilepsia.cl.

Meeting

Regular meetings took place the second Saturday of every month during 2015 and 2016.

- **MEETING No. 151**
Saturday, January 10th, 2015:
Update on sleep obstructive apnea and its influence in the management of epilepsy.
Dr. Mauricio Bravo, Neurologist, Military Hospital.
- **MEETING No. 152**
Saturday, March 14th, 2015.
Annual General Meeting of the Society of Epileptology of Chile.
- **MEETING No. 153**
Saturday, April 11th, 2015.
Epilepsy in 15-year-olds and older patients with Down Syndrome.
Dr. Darío Ramírez, Neurologist, Salvador Hospital.
- **MEETING No. 154**
Saturday, May 9th, 2015.
An Update in Panayiotopoulos Syndrome.
Dr. Patricia Alfaro, Pediatric Neurologist, San Juan de Dios Hospital.
Friday, June 5th and Saturday, June 6th, 2015.
XV Winter Symposium of Epilepsy, Hotel Neruda - Santiago.
- **MEETING No. 155**
Saturday, July 11th, 2015.
Super-refractory status epilepticus: The surgical alternative.
Dr. Hernán Acevedo, Neurosurgeon, Asenjo Institute of Neurosurgery.
- **MEETING No. 156**
Saturday, August 8th, 2015.
Association between Posterior Reversible Encephalopathy Syndrome (PRES), seizures and epilepsy. A clinical case report.
Dr. Kathleen Batalla, Physician, Emergency Department, Padre Hurtado Hospital.
- **MEETING No. 157**
Saturday, September 12th, 2015.
Epilepsy and Immunology.
Dr. Raimundo Uribe, Neurologist, Catholic University of Chile.
- **MEETING No. 158**
Saturday, October 17nd, 2015.
Radiosurgery in epilepsy.
Dr. Claudio Lühr, Neurosurgeon, Military Hospital.
- **MEETING No. 159**
Saturday, November 14th, 2015.
A new epilepsy program in Chile.
Dr. Lilian Cuadra, Pediatric Neurologist, Asenjo Institute of Neurosurgery.
- **MEETING No. 160**
Saturday, December 12th, 2015.
Clinical Case: Extreme delta brushes.
Dr. Cayetano Napolitano, Neurologist, Military Hospital.
- **MEETING No. 161**
Saturday, January 9th, 2016.
Quality of Life in Epilepsy.
Dr. Juan Luis Moya, Pediatric Neurologist.
Dr. Luis Calvo Mackenna Hospital.
- **MEETING No. 162**
Saturday, March 12th, 2016.
Annual General Meeting of the Society of Epileptology of Chile.
- **MEETING No. 163**
Saturday, April 9th, 2016.
Intoxication caused by phenytoin.
Dr. Darío Ramírez, Neurologist, Salvador Hospital.
- **MEETING No. 164**
Saturday, May 7th, 2016.
Malignant migrating partial seizures of infancy: Case report.
Dr. Ignacia Schmidt, Pediatric Neurologist, Catholic University of Chile.
Friday, June 3th and Saturday, June 4th, 2016.
XVI Winter Symposium of Epilepsy, Hotel Neruda - Santiago.
- **MEETING No. 165**
Saturday, July 9th, 2016.
Less-frequent epileptic syndromes in infancy.
Dr. Jonathan Velásquez, Pediatric Neurology Resident, Dr. Luis Calvo Mackenna Hospital.
- **MEETING No. 166**
Saturday, August 20th, 2016.
Usefulness of the ASL sequence in MRI of patients with epilepsy.
Dr. Francisco Torres, Neuroradiology Resident, Asenjo Institute of Neurosurgery.
- **MEETING No. 167**
Saturday, September 10th, 2016.
Neuropsychologic assessment in epilepsy.
Ps. Macarena Vásquez, Psychologist, Catholic University of Chile.
- **MEETING No. 168**
Saturday, October 22nd, 2016.
Unitemporal versus bitemporal epilepsy: A video analysis.
Dr. Cayetano Napolitano, Neurologist, Military Hospital.



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- **MEETING No. 169**
Saturday, November 12th, 2016.
Atypical features in benign epilepsy of childhood with centrotemporal spikes.
Dr. Marcelo Bascur, Pediatric Neurology Resident,
Dr. Luis Calvo Mackenna.
- **MEETING No. 170**
Saturday, December 17th, 2016.
Autoimmune encephalitis and anti-GABA-A receptor antibodies.
Dr. Pablo González, Neurologist, La Florida Hospital/Clinica Las Condes.

Summary of Activities in 2015/16

Congresses, Courses and Symposia

XV Winter Symposium in Epilepsy 2015

On June 5th and June 6th, 2015, the XV Winter Symposium of Epilepsy was held at the Neruda Hotel. Its motto was "Epilepsy: A modern approach".

Organizing Committee: Dr. Ledia Troncoso – Dr. Scarlet Witting (Presidents), Dr. Perla David, Dr. Marcelo Devilat, Dr. Fernando Ivanovic-Zuvic, Dr. Cayetano Napolitano, Dr. Juan Moya, Dr. Carla Manterola.

It included conferences by leading local neurologists and neurophysiologists, and presentation of 18 original works (posters).

XXXIII SOPNIA Congress 2015

From November 11th to November 13th, 2015, the XXXIII Congress of the Society of Psychiatry and Neurology of Childhood and Adolescence (SOPNIA) was held in the city of Coquimbo. This event, entitled, "Diagnostic and therapeutic horizons", was sponsored by our Society.

World Congress of Neurology 2015

From October 31st to November 5th, 2015, the Society of Neurology, Psychiatry and Neurosurgery (SONEPSYN) participated in the organization of the XII World Congress of Neurology, celebrated in the city of Santiago. This event was supported by our Society.

XVI Winter Symposium in Epilepsy 2016

On June 3th and June 4th, 2016, the XVI Winter Symposium of Epilepsy was held at the Neruda Hotel. Its motto was "Epilepsy: More than seizures".

Organizing Committee: Dr. Hernán Acevedo - Dr. Juan Moya (Presidents), Dr. Carla Manterola, Dr. Perla David, Dr. Cayetano Napolitano, Dr. Marcelo Devilat.

It included conferences by leading local neurologists and neurophysiologists, and presentation of 17 original works (posters).

XXXIV SOPNIA Congress 2016

From November 14th to November 16th, 2016, the XXXIV Congress of the Society of Psychiatry and Neurology of Childhood and Adolescence (SOPNIA) was held in the city of Puerto Varas. This event, entitled, "Between lakes and volcanoes", was sponsored by our Society.

LXXI SONEPSYN Congress and LIX Chilean Neurosurgery Congress 2016

From October 6th to October 8th, 2013, the Society of Neurology, Psychiatry and Neurosurgery (SONEPSYN) celebrated its LXXI Congress in the city of Coquimbo; at the same time, the LIX Chilean Neurosurgery Congress was held. These events were sponsored by our Society.

Celebration of Latin American Day of Epilepsy

We celebrated the Latin American Day of Epilepsy on September 9th, 2016. The Chilean League Against Epilepsy organized diverse activities to commemorate this day, including the participation of patients and their families. Dr. Perla David, a member of our board, participated in this celebration.

New Members

Between the years 2015 and 2016, the Society received the following new members:

1. Dr. Mauricio Bravo (January 2015)
2. Dra. Patricia Alfaro (May 2015)
3. Dra. Kathleen Batalla (August 2015)
4. Dr. Reinaldo Uribe (September 2015)
5. Dr. Claudio Lühr (October 2015)
6. Dr. Ignacia Schmidt (May 2016)
7. Dr. Jonathan Velásquez (July 2016)
8. Dr. Francisco Torres (August 2016)
9. Ps. Macarena Vásquez (September 2016)
10. Dr. Marcelo Bascur (November 2016)
11. Dr. Pablo González (December 2016)

Working Hours/Opening Hours

Luisa Esparza is our current secretary. Her working schedule is: Mondays, Wednesdays and Fridays from 18.30 to 20.30 hrs. Phone: +56222310172.

Fax: +56222340671. E-mail: socepchi@gmail.com

Summary of Activities in Relation to Global Campaign in 2015 and 2016

National Affiliations

Our Society maintains continuous interaction with:

The Society of Neurology, Psychiatry and Neurosurgery (SONEPSYN);

The Society of Psychiatry and Neurology of Infancy and Adolescence (SOPNIA);

The Chilean Society of Pediatrics (SOCHIPE);



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The Chilean Society of Clinical Neurophysiology (SOCHINEUROFISIOLOGÍA); and the Association of Leagues Against Epilepsy, Chile (ANLICHE). Various Society members participate in the Epilepsy Regulatory Group of the Ministry of Health of Chile (MINSAL).

International Affiliations

The Society is a member of the Latin American Affairs Committee of the International League Against Epilepsy.

Celebration of Latin American Day of Epilepsy

As we mentioned previously, we celebrated the Latin American Day of Epilepsy on September 9th, 2016. The Chilean League Against Epilepsy organized diverse activities to commemorate this day, in which Dr. Perla David participated actively.

Educational Activities

Continuing Medical Education

Between September and November of the current year, we performed the first version of our Continuing Medical Education (CME) course, named "Updates in Epilepsy". This course was presented in the e-learning format, and it included the participation of more than 100 health professionals (including general physicians, neurologists, pediatric neurologists and residents, among others). It became a unique opportunity to review topics of general interest related to the epilepsies.

Webpage

Our website, www.epilepsiadechile.com, is available for members and the general public. We have published information about the Society and issues related to epilepsy, in the following sections:

1. Index
2. Introduction
3. Activities (Regular meetings, Winter Symposium of Epilepsy, Continuing Medical Education)
4. Notes (Updates on epilepsy, History of epilepsy)
5. News about epilepsy
6. Staff and associates
9. Links to ILAE, IBE, WHO and MINSAL; and to the Chilean Journal of Epilepsy
10. Contact

The site has played an important role for university students, who are the most frequent users asking for references, as well as for patients and their relatives. We have collaborated with a national diffusion of epilepsy-related topics actively through this website, uploading some of the presentations of our regular meetings, as well as the contents of our Winter Symposium of Epilepsy, with prior authorization from its authors.

Library

Our library, located at the headquarters of the Society, receives a great number of journals and other publications.

Epilepsia, the official publication of the ILAE, is received in our offices from 1999 to the current date, and it is available for members at the headquarters of the Society of Epileptology of Chile, in addition to being online.

Future Plans

XVII Winter Symposium of Epilepsy: "Epilepsy as a marker of disease"

On June 2th and June 3th, 2017, the XVII Winter Symposium of Epilepsy will take place at the Neruda Hotel. Its official motto will be "Epilepsy as a marker of disease". The Organizing Committee has already released the academic program, and original works are being received currently at the email of our Society.

Organizing Committee: Dr. Juan Salinas – Dr. Juan Moya (Presidents), Dr. Perla David, Dr. Cayetano Napolitano, Dr. Carla Manterola, Dr. Darío Ramírez.

LXXII SONEPSYN Congress and XIII Hispanic-Latin American Congress of Eating Disorders and Obesity through the 2017 cycle. Entitled "Bridges among our specialties", it will be celebrated at Hotel del Mar, Viña del Mar, from November 9th to November 11th, 2017.

XXXV SOPNIA Congress 2017

Under the name "Tearing down the walls", it will be hosted at Gran Hotel Pucón, Pucón, Araucanía Region, Chile, from November 15th to November 17th, 2017.

Continuing Medical Education

Considering the successful execution of our first e-learning course, we have plans of preparing a second version during 2017. It shall be related to epilepsy and pharmacology, as well as analyzing of clinical cases.

Regular Meetings

Our schedule for regular meetings in 2017 is listed below.

- January 14th, 2017 (already performed by Dr. Juan Moya: "Normal variants in the electroencephalogram").
- March 10th, 2017 (Annual General Meeting of the Society of Epileptology of Chile)
- April 8th, 2017
- May 13th, 2017
- June 10th, 2017



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- July 8th, 2017
- August 12th, 2017
- September 9th, 2017
- October 14th, 2017
- November 11th, 2017
- December 9th, 2017

Officer Election Date

Our new board and officers will be elected during the Annual General Meeting of the Society of Epileptology of Chile, which will be conducted on March 10th, 2017.

Report by

Dr. Cayetano Napolitano, President. Dr. Perla David, Director. Dr. Juan Moya, Treasurer

CHINA ASSOCIATION AGAINST EPILEPSY

Publications

Journal of Epilepsy (first issue 2015); Guideline of Diagnosis and Treatment to Epilepsy, 2nd Edition (2015); Epilepsy Knowledge: A education book to people with epilepsy (2016).

Meeting

6th CAAE International Epilepsy Forum (2015); Meeting of the Establishment of Tan Qi Fu Neurosurgery Development Foundation (2016); SEEG and brain localization academic committee Founding Conference (2016); 1st CAAE Neurosurgery Annual Meeting (2016); 5th CAAE EEG and Neuro-electrophysiology Congress (2016); International Symposium of Economic Burden of People with Epilepsy (2016); 2016 Temple of Heaven International Epilepsy Congress (2016)

Summary of Activities in 2015/16

1. CAAE Speaking Tour of the "Guideline of Diagnosis and Treatment to Epilepsy", took place in ten cities in China: Fuzhou, Kunming, Nanjing, Changchun, Shijiazhuang, Haikou, Taiyuan, Qingdao, Suzhou, and Taizhou.
2. "Young Physicians Going West Program", a program organized by CAAE aimed to improve the capacity of diagnosis and treatment to epilepsy in less-developed areas in China. In 2016, this program has been conducted in 11 areas, including Binzhou (Hunan province),

- Mianyang (Sichuan province), Shiyan (Hubei province), Jinzhou (Liaoning province), Xuzhou (Jiangsu province), Yanji (Jilin province), Lanzhou (Gansu province), Chifeng (Neimenggu province), Guiyang (Guizhou province).
3. DANDELION Physician Education Program: 'Spreading the seeds of knowledge to improve epilepsy care for patients', is a tailored medical education program to improve the anti-epilepsy medical practice. The objective is to provide disease training to general neurologists from Tier-3 cities to advance their ability to make better treatment decisions for patients.
 4. CAAE Epilepsy Scientific Research Foundation has supported 11 projects among 33 applications in 2016.
 5. "NEW Program" has been conducted for young epileptologists aimed to improve their clinical and scientific research skills via symposiums and group meetings.
 6. CAAE launched the "Galaxy Program", a training program offered to primary health workers and physicians.
 7. CAAE successfully collaborated with the "World Health Foundation" for "Project Hope", which aimed to provide education and help to children with epilepsy and their parents.
 8. CAAE continually develops the provincial chapter in China. Chapters of Henan, Fujian, Zhejiang, Shanghai and Guangxi were founded in 2016.
 9. June 28, 2016 was the 10th "International Epilepsy Caring Day (IECD)" in China. This year's theme of IECD was "Ginko leaf logo warming your life with epilepsy". CAAE and 21 provincial chapters conducted the IECD grand philanthropic activities, including free medical consultations, education lectures, online Q&A, etc. Two hundred hospitals in 26 provinces conducted these activities, and 20,000 people with epilepsy have benefitted from these activities.
 10. CAAE conducted the promotional activity of the International Epilepsy Day in late January 2016, through media, internet and WeChat. CAAE also supported the Art Competition for International Epilepsy Day at the end of 2016, by advertising and sending 20 pieces of artwork to IBE.
 11. CAAE is developing the official website (www.caae.org.cn) and WeChat platform. At the end of 2016, the number of followers reached 20,000 in China, including physicians and people with epilepsy.



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Summary of Activities in Relation to Global Campaign in 2015 and 2016

Through 2016, the national project on management of epilepsy control in rural areas of China (2005 – present) was funded 4 million CNY/yr (0.64 m USD) by the State government, starting in 2005 in ten provinces; now in 2014 in 18 provinces, 135 counties, funding increased to 15.6 million CNY/Yr (2.5 m USD). The project treated and followed 98,495 people with epilepsy, trained 1,497 province level doctors and 30,004 township and village doctors, and established 444 special outpatient epilepsy.

Educational activities

1. ASEPA training course of epilepsy syndrome (Chifeng 2016)
2. 6th Advanced International Course of Clinical Epileptology (Chengdu 2016)
3. 2nd Training Course of SEEG and Epilepsy (Beijing, 2016)
4. CAAE EEG training and examination (Beijing, 2016)

Activities in Conjunction with Local IBE Affiliate

1. CAAE successfully conducted the Psychological Intervention Demonstrate Project for PWE, 2016, through knowledge education and psychological intervention by professional psychiatrists and psychologists. The objectives included:
 - i. Reduce psychological problems;
 - ii. Encourage blending into society;
 - iii. Improve the adherence to treatment;
 - iv. Strengthen family support;
 - v. Provide correct knowledge of the disease to PWE and the public. This project was financially supported by the Ministry of Civil Affairs of People's Republic of China.
2. Mr. Zhigang Wang, an outstanding person with epilepsy, recommended by CAAE, was awarded the "Golden Light Award" at the 11th AOECC.

Future Plans

1. Continually hold domestic and international academic exchanges and cooperation related to epileptology; and to provide training for epileptology related professionals to improve their ability to diagnose and treat epilepsy, especially for primary healthcare workers in resource-poor provinces.
2. More publications including guidelines, expert opinions and white papers of the economic burden of epilepsy in China will be published in 2017.

3. To establish more epilepsy-related specific funding to promote the research capacity of epileptologists.
4. By collaborating with IBE, we will continually publicise, educate, and promote the knowledge of epilepsy prevention and control, and provide consultative services and help to people with epilepsy and their family members through public media, internet, and online/offline activities.
5. Attempt to promote and protect the legal rights of people with epilepsy.
6. To provide consultancies to the government for related policy decisions.

Officer Election Date

December 2018

Report by

Ding Ding

COLOMBIAN LEAGUE AGAINST EPILEPSY

Summary of Activities in 2015/16

Colombian League against Epilepsy (LCE) needed sudden "aggiornamento" due to lack of activities and responsibilities in light of the government's rules and laziness in scientific tasks and same laxity in handling the economics. For these reasons, it was necessary to convene a general assembly and vote for a new Board of Directors.

Achievements:

1. Reforms of bylaws in order to put the role of LCE in front of new concepts of human rights given by Law 1414/10 (protection of people with epilepsy).
2. Organization of regional chapters in every province (22 chapters). We are still working on this task.
3. Colombia has 100% of its population covered by health. So our aim is based on three aspects:
 - A. Defence of Human Rights, according to the Law 1414/10
 - B. Improve research and education in epilepsy, according to Foundation Epilepsy Award Margaret Merz de Fandiño and Law 1414/10
 - C. Propitiate rehabilitation of people with epilepsy.
4. To organize every two years the Colombian Epilepsy Congress (with IBE Colombian chapter). The last one took place three months ago in Cartagena.
5. Tie together other professionals as rehabilitators, psychologists, lawyers, dentists, social workers and general practitioners. We believe that neurologists are a little unenthusiastic.



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6. We will organize sub-chapters in every town around the country.

Report by

Jaime Fandiño-Franky, President

CROATIAN LEAGUE AGAINST EPILEPSY

Meeting

The League meets 2-3 times a year.

Summary of Activities in 2015/16

- The main activity during the term 2015-2016 was the organization of the 12th Croatian Symposium on Epilepsy which took place in Zadar from October 20-23, 2016. During the Symposium, the General Assembly was held and new officers were elected. The new president of the Croatian League Against Epilepsy (CLAE) is professor Silvio Basic.
- CLAE took part in the organization of the Adriatic Neurology Forum 2016. (ANF 2016.), an important regional meeting where neurologists and neuropediatricians from our region have an opportunity to hear lectures given by the leading world experts.
- CLAE participated at the 45th Symposium of Croatian Child Neurology Society.
- CLAE participated in activities for Epilepsy Day in Croatia (February 2015 and 2016). Events were organized by the CLAE, Croatian Child Neurology Society and Association for Epilepsy.

Educational Activities

As mentioned above, the 12th Croatian Symposium on Epilepsy took place in Zadar from October 20-23, 2016. There have been more than 100 participants and the feedback from the conference was overwhelmingly positive. Professor Meir Bialer was the keynote speaker and his participation was highly valued by attendees. A lecture competition for young doctors is held during the Symposium, with prizes awarded for the best lectures. CLAE also took place in the organization of several workshops on epilepsy.

Future Plans

CLAE will continue to promote the development of epileptology in Croatia and to participate in the education of neurologists and epilepsy nurses. We would like to improve presurgical diagnostic procedures for epilepsy, as well as epilepsy surgery in adults and children with refractory epilepsy. We hope to implement a new model for transition and transfer of patients with epilepsy from pediatric to adult epilepsy care in daily practice.

Report by

Silvio Basic, President

CUBAN LEAGUE AGAINST EPILEPSY

Publications

1: Morales-Chacon LM, Alfredo Sanchez Catusus C, Minou Baez Martin M, Rodriguez

Summary of Activities in 2015/16

Plan of action and strategies on epilepsy appropriate to the conditions of the country with the objective of promoting clinical areas, education, research, legislative framework, etc. Participation in investigations framed in national and international collaboration projects (CYTED and CONACYT) Incorporation of Epilepsy issues as part of the training program for third year residents of the specialty of psychiatry, and of the graduates of "Psychiatric Emergencies" and "Emergencies Doctors" of the Enrique Cabrera School of Medicine. National courses for epilepsy and electroencephalography training. National courses for epilepsy in the APS National Epilepsy Annual Conference.

Summary of Activities in Relation to Global Campaign in 2015 and 2016

Publication of books including Guidelines for the *Treatment of Drug-resistant Epilepsies in Cuba. What an APS Doctor Should Know About Epilepsy.*

Educational Activities

III Course-Workshop
ALADE, Havana Cuba
2014

Epilepsy update course in a central province of Cuba. Sancti Spiritus specialists have taken ALADE scholarships for short internships in epilepsy centres in Latin America. Participation in the editions of LASSE IX, X. From 27-29 April 2015, the regional course "Update on epilepsy" was carried out at the Hospital Camilo Cienfuegos de la Province of Sancti Spíritus, Cuba with the participation of specialists from the country's central provinces, as well as residents from other Latin American countries. The course organizers and teachers were:

- Dr. C. Lilia Morales Chacón International Center for Neurological Restoration, Cuban Chapter President of the International League Against Epilepsy.
- Msc Juan M Rojas de Dios, Secretary of the Spanish Society of Neurosciences (SONECUB). Hospital Camilo Cienfuegos Sancti Spiritus.



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- Dr. Teresa Montes de Oca, President of the Espirituan Chapter of the Society of Neurosciences of Cuba (SONECUB). SONECUB. Hospital Camilo Cienfuegos Sancti Spiritus.
- Dr. C. Valía Rodríguez, Center for Neuroscience in Cuba. Member of the Society of Neurosciences of Cuba (SONECUB).
- Dr. Lidia Charro Núñez Neuroscience Center of Cuba. Member of the Society of Clinical Neurophysiology (SONECUB). University of Sciences of Havan. Faculty Victoria De Girón. Playa Department of Clinical Neurology.

Title “Drug-Resistant Epilepsies: Clinical and Surgical Aspects”. Type of Activity: Course-training. Havana Cuba, November 2015

Activities in Conjunction with Local IBE Affiliate

Survey of family members, patients, and professionals on stigma in epilepsies. Reunion with relatives and patients.

Future Plans

Develop a strategy that guarantees availability to the fundamental diagnostic and treatment media with special emphasis on intractable epilepsy with medication. Need to implement epilepsy surgery in children. Promote elective courses of epilepsy in the medical career training plan. Use the different postgraduate forms (courses, diplomas, master’s degrees, trainings) to encourage the preparation of non-specialized health personnel in primary and secondary care in diagnosis and treatment. To promote the development of research in the field of epileptology. Consensus participation with the Ministry of Public Health in the country, in the development of the action plan and strategies on epilepsy.

Officer Election Date

Dec 2017

Report by

Lilia Morales Chacon

EGYPTIAN SOCIETY AGAINST EPILEPSY

Publications

- Assessment of precipitating factors of breakthrough seizures in epileptic patients. Manal Al-Kattan1, Lamia Afifi MD 2, Reham Shamlou1, Emad El Din Mostafa. *Egypt J Neurol Psychiatry Neurosurg* 52 (2015) 165-171
- Epilepsy prevalence in Al-Manial Island, Egypt. A door-to-door survey. Saher Hashema, Manal Al-Kattana, Sahar Y. Ibrahim, Nevin M.

Shalabya, Reham M. Shamloula, Mohammad Farraga, *Epilepsy Research* 117 (2015) 133–137.

- Case report: Homozygous PRRT2 mutation in an ICCA Egyptian family with reduced penetrance. Nirmeen A. Kishk, Wessam E. Sharaf-Eldin, Heba Saher, Mona Essawi. *Meta Gene online* 18 Dec. 2016.

Summary of Activities in 2015/16

The Purple Day for Epilepsy Awareness for the public and medical students was held on 25th March 2015 and 30th March 2016.

Epilepsy awareness session for paramedical staff and hospital personnel highlighting the true concept of Epilepsy, how to deal with acute seizures and the services provided by the “Cairo University Epilepsy Unit CEUE” was held on 30th March 2016.

A Facebook page was created with public educational materials and for uploading announcements for epilepsy awareness activities.

Educational activities

- Two comprehensive epilepsy meetings were held during March 2015 and 2016. The first meeting focused on “When Can EEG Take the Lead in Epilepsy diagnosis” during which the following lectures were presented: Maturation of temporal lobe seizure semiology, Recurrent psychosis as manifestation of epilepsy, Ictal EEG patterns, Diagnosis of non-convulsive seizures... is it easy?? The second meeting was under the title “Pediatric Epilepsy...for a Safe Future” it addressed the following topics: Epileptic seizures in inborn errors or metabolism; a diagnostic approach, Video presentations of non-epileptic events in young age, Febrile convulsions & Frequently asked questions (FAQ) and interesting case reports.
- Epilepsy sessions during the annual meeting of the neurology department were held during December 2015 and 2016.
- Undergraduate and post graduate educational and clinical training sessions on epilepsy were held throughout the academic year.
- The first workshop on epilepsy classification and seizure semiology was held on the 7th of December 2016.
- A special session for epilepsy was held at the neuro-pediatric workshop
- Webinar on Epilepsy was successfully organized in December 2016.
- Biweekly morning EEG teaching sessions at the Neurology Department, Cairo University for junior neurologists.

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Future Plans

- Construct ESAE-website that may contain CUEU services, information on meetings and epilepsy related events, educational materials (handouts and videos), and a section for public awareness and how to contact the CUEU Team.
- Journal club gathering either monthly or biweekly to discuss important research results and updates on epilepsy.
- Publications of ESAE-newsletter.

Officer Election Date

26 March 2018

Report by

Prof. Dr. Ahmed Talaat El-Ghonemy, Prof. Dr. Nermin A .Kishk, Dr. Reham M. Shamloul

FINNISH EPILEPSY SOCIETY

Finnish Epilepsy Society is a Chapter of the International League Against Epilepsy (ILAE) in Finland. Members of the professional society consist of 230 clinicians and scientists working within epileptology. Finnish Epilepsy Society promotes the research, treatment and prevention of epilepsy and the exchange of medical and scientific information related to epilepsy in Finland. The society is active also in international collaboration, especially in ILAE-related commissions and projects.

Educational Activities

National teaching courses

19.-20.3.2015 "Good treatment policy in Epilepsy belongs to all - Epilepsian hyvä hoito kuuluu kaikille". program consisted of lectures about good treatment policies in epilepsy for fertile women, disabled persons, elderly citizens, and persons with rare epilepsy. The lecturers were domestic epilepsy experts. The course had 156 participants including lecturers. Feedback obtained from the course was good/excellent.

30.9.2016 "New insights to diagnosis and treatment of epilepsy by using genetic tools - Genetiikan menetelmillä uusia näkökulmia epilepsian diagnostiikkaan ja hoitoon". The program consisted of lectures about possibilities of gene technology methods in epilepsy and how they should be used in clinical practice as well as the need for genetic counseling. Visiting lecturer was professor Aarno Palotie from Harvard University, USA. Other lecturers were domestic experts in the field. The course had 48 participants including lecturers. Feedback obtained from the course was good/excellent. A satellite symposium was also organized in co-operation with Eisai AB. The

symposium provided the latest information on research findings of perampanel and clinical experience in Finland. Lecturers were Professors Eugen Trinkla (Austria) and Reetta Kälviäinen (Kuopio, Finland).

Finnish Epilepsy Society has collaborated with UCB Pharma Oy Finland in organizing annual Epitalkoot®- courses. Two courses were organized in the 2015-2016 period. 8.-9.5.2015 "Newly-diagnosed epilepsy - Vastadiagnosoitu epilepsia". International visiting lecturer was Prof. Anthony Marson (University of Liverpool & The Walton Centre NHS Foundation Trust, Liverpool, UK), who gave a lecture about "Treatment response and prognosis in newly diagnosed epilepsy". The program also consisted of other lectures and interactive workshops led by domestic epilepsy experts. The course had 120 participants.

13.-14.5.2016 "What to do when seizures continue? - Mitä tehdä kun kohtaukset jatkuvat?" International visiting lecturer was Prof. Ley Sander (UCL Institute of Neurology London, Scientific Director of SEIN, the Epilepsy Institute of the Netherlands Foundation), who gave a lecture about "Practical use of new AEDs as adjunctive therapy". The program also consisted of other lectures and interactive workshops led by domestic epilepsy experts. The course had 139 participants.

Local education courses

Finnish Epilepsy Society has since 2006 organized local courses around Finland in collaboration with Eisai AB, Fenno-Medical Oy, Orion Pharma ja UCB Pharma Oy Finland. The topic of the courses in 2015 was "Good treatment policies in epilepsy and the use of valproic acid in fertile women". The 2016 topic was "New ILAE definitions of epilepsy and epileptic seizures".

Table. Local courses organized in 2015 and 2016.

	Location	Date	Participants
2015	Jyväskylä-Mikkeli	16.4.2015	40
	Helsinki	15.9.2015	30
	Lahti	17.9.2015	20
	Tampere-Hämeenlinna	1.10.2015	46
	Kuopio-Joensuu (etä)	8.10.2015	37
	Oulu- Kajaani, Kemi, Kokkola, Rovaniemi	11.11.2015	55
	Turku	12.11.2015	41
	Seinäjoki	19.11.2015	33
	Pori	24.11.2015	24
		Location	Date
2016	Hämeenlinna	24.8.2016	17
	Tampere	25.8.2016	37
	Pori	5.9.2016	10
	Seinäjoki	6.10.2016	21
	Oulu, Kajaani, Kemi, Kokkola, Rovaniemi	18.10.2016	66



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Meeting

Society organizes an annual meeting every spring that is open for all members of the society. Annual report, financial statement of the previous year and action plan for a the next year are presented and approved the meeting. New board members are also selected annually for one-year period. The annual meeting in 2015 was held on 20th March 2015. New members of the board were selected and they were (supplementary member in brackets) Reetta Kälviäinen (Jukka Peltola), Henna Jonsson (Sirpa Rainesalo), Salla Lamusuo (Markus Müller), Terhi Pirttilä (Tarja Puumala), Riikka Mäkinen (Johanna Uusimaa) ja Päivi Olsén (Hannu Heiskala). The same members were selected to continue at the annual meeting of 2016 that was held 17th March 2016.

Board Meetings

The board members of the Society in 2015-2016 were Reetta Kälviäinen (President), Terhi Pirttilä (Secretary), Henna Jonsson (Treasurer), Salla Lamusuo, Riikka Mäkinen and Päivi Olsén. The board organized meetings 5 to 6 times annually.

International Collaboration

Finnish Epilepsy Society is a Chapter of the International League Against Epilepsy (ILAE). Members of the Society have several international positions: Professor Jukka Peltola is a member of the ILAE Classification and Terminology Commission and Professor Reetta Kälviäinen is a Chairwoman of the Epilepsy Scientific Panel of European Academy of Neurology (EAN).

Domestic Collaboration

Members of the Finnish Epilepsy Society participate in the national committee to create guidelines for the treatment of epilepsy in Finland (Käypä Hoito-committee). In 2016, the Käypä Hoito committee published guidelines for treatment of Status Epilepticus. Similar guidelines have previously been published for treatment of epilepsy in children and febrile seizures (in 2013) and treatment of epilepsy in adults (in 2014).

The Finnish Epilepsy Society works in close collaboration with the Finnish Epilepsy Association, a Chapter of IBE. Professor Reetta Kälviäinen, docent Liisa Metsähonkala and MD, PhD Hanna Ansakorpi are members of a specialist committee of the Finnish Epilepsy Association.

Finnish Epilepsy Society has participated in actions of "Suomen Aivot ry", which is a member of European Brain Council.

Members

Finnish Epilepsy Society has 230 members (as of 31.12.2016). In 2015-2016, the society did not collect membership fees.

Future Plans

In 2017, the biggest educational activity will be the International Kuopio Epilepsy symposium, which will take place in Kuopio, Finland in March 2017. Finnish Epilepsy Society takes part in organizing the meeting and members of the society will also be lecturers in the symposium. Local educational courses will also be continued in the coming year. The Society continues to collaborate with the Finnish Epilepsy Association to promote the knowledge of epilepsy and equal access to high-quality care in Finland.

FRENCH LEAGUE AGAINST EPILEPSY

Publications

Les cahiers d'Épilepsie: March and October 2016

Meeting

JFE 2016 Toulouse November 7 to 10, 2016 (French annual epilepsy meeting)

Summary of Activities in 2015/16

3-Summary of Activities in 2015 and 2016

Board Achievement:

- Elaboration of a charter on the care pathways in epileptology following the press conference held on November 2015 and in relation to the task force created under the auspices of the SFN, SFNP, and ANLF, FFRE and Epilepsie France. After several meetings, including the Executive Committee meetings, a text was voted on defining several levels of care management, and for each level what the roles and necessary means are.
- This text was then sent to the appropriate health government authorities. P. Derambure met with the General Director of Public Health and was able to express our thoughts and expectations regarding epilepsy care management. Furthermore, the media coverage regarding the teratogenic adverse events of valproate justified posting on the LFCE website recommendations on the care management of epilepsy during pregnancy. This answers most of the questions directed to the LFCE on this topic, and we also refined the position of the LFCE, SFNP, SFN as well as the FFRE scientific societies during a press conference held on 3/10/2016.
- Upon the request from the National Social Security Agency (CNAM), a proposal regarding the creation of a new medical act "EEG epilepsy" to better reflect the reality and help financially valorize epilepsy outpatients' visits and EEG. We are awaiting the approval of the French National Authority for Health (HAS).



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- **Transparency:** The LFCE would like to reflect on its partnership with the industry and the transparency needed for these links. We solicited the advice of Pierre LeCoz, President of the Deontology and Prevention of Conflict of Interests committee. The conflicts of interests of the LFCE will be published on the LFCE website.
- **Work and epilepsy:** The Administration Committee consulted with A Didelot, who coordinates the “work and epilepsy” outpatients clinic in France, with the objective to increase the number of clinics, and look at funding possibilities through the AGEFIPH innovation department.
- **Therapeutic Education Commission:** The annual conference took place in May 2016, following the meeting of the Administration Committee, over a two-day period at La Teppe, gathering most centres already involved in this process.
- **Communication:** The LFCE is active on social networks: Twitter and Facebook. The website has many visitors, especially the section on mortality. The articles on specific issues (e.g. pregnancy, sports, driving licenses) are on the website, as well as a detailed section on valproate. A new format is being looked at for the LFCE magazine: the contract with expression santé, for which we are unable to find enough sponsors, will be denounced, and we will look at a collaboration with the Neurological Journal (*Revue Neurologique*).
- **Mission:** The mission of the LFCE Young Physician commission is, besides promoting the presence of the LFCE on the social networks and the organization of the JEEP, to select the best posters presented during the JFE Toulouse with a 1,000€ award, allowing for the participation to the next JFE.
- **RSME:** Remains very active, LFCE finances two hospital vacations for a psychologist. A new informational leaflet on RSME and a leaflet on epileptic seizure risks dedicated to patients and their family were finalized.

Summary of Activities in Relation to Global Campaign in 2015 and 2016

International affairs: The French Chapter proposed the definition of European guidelines on epilepsy psychiatric comorbidities, and participated on the election of the new ILAE president (Samuel Wiebe, Canada).

Educational Activities

2016 Bursaries. 2.5 post-doctorate bursaries will be granted, each one in the amount of 30,000€.

The common FFRE and LFCE call for project was attributed to the research project on Vitamin D and epilepsy headed by Dr F Chassoux (Paris Ste Anne). CME training for registered nurses (DPC). A second

session took place at La Teppe in 2015, a third one took place in October 2016. As a reminder, the goal of this training is to educate specialized epilepsy nurses based on the Anglo-Saxon model. An agreement was reached with the HAS Rhone-Alpes for delegating precise tasks to nurses specifically trained according to this protocol.

A debate was conducted with L. Maillard to adapt the epileptology InterUniversity Diploma (DIU). In fact, its two-year duration discourages a number of applicants. We are looking at reformatting the program over a one-year period, using online classes. The CPE is obsolete and has been replaced by the Educational Days on Practical Epileptology (JEEP). The program is designed by members of the young Physician Commission.

Future Plans

JNLF 2017: The program for the LFCE session was built around the topic of epilepsy in women.

JFE 2017: Marseille October 9 to 12.

Officer Election Date

The board was re-elected during the Administration Committee annual meeting on February 2016: President P. Derambure, General Secretary C. Marchal, Treasurer B. Martin, Vice President of the Scientific Committee F. Bartolomei, VP of communication: L. Vercueil, VP of international affairs: Ph. Rylin, VP of care networks and pathways: S. Rheims, VP of paramedical professionals: M. Prévos-Morgan.

Report by

Cecile Marchal (general secretary of the LFCE, French chapter)

FYR MACEDONIA: MACEDONIAN LEAGUE AGAINST EPILEPSY

Publications

Epilepsy

Meeting

2. International Symposia on malformations of cortical development and epilepsy, September, 2016, Ohrid, R. Macedonia (lecturers: Prof Meir Bialer, Israel; Dr. Imad Najm, USA; Prof N. Jovic, Serbia; Prof D. Sokic, Serbia; Prof S. Basic, Croatia; Prof D. Sporis, Croatia; Dr. A. Ristic, Serbia)

Summary of Activities in 2015/16

1. Epilepsy - official journal of Macedonian League, two issues per year; Editor in Chief - Emilija Cvetkovska



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2. International Symposia on Malformations of cortical development and epilepsy, September, 2016, Ohrid, R. Macedonia (lecturers: Prof Meir Bialer, Israel; Dr. Imad Najm, USA; Prof N. Jovic, Serbia; Prof D. Sokic, Serbia; Prof S. Basic, Croatia; Prof D. Sporis, Croatia; Dr A. Ristic, Serbia)

Summary of Activities in Relation to Global Campaign in 2015 and 2016

Purple Day for raising public awareness of epilepsy, March 2016, Skopje, R. Macedonia.

Educational Activities

International Workshop on AED, September, 2016, Ohrid, R. Macedonia. Prof Meir Bialer, Israel; Prof Emilija Cvetkovska, Macedonia

Future Plans

Continue to publish epilepsy organization of workshops on selected topics.

Report by

Emilija Cvetkovska, President

GEORGIAN LEAGUE AGAINST EPILEPSY

Publications

- Kasradze S., Gogatishvili N., Lomidze G., Ediberidze T., Lazariashvili M., Khomeriki K., Mamukadze S., Metreveli M., Gagoshidze T., Tatishvili N., Tomson T. Cognitive functions in children exposed to antiepileptic drugs in utero - study in Georgia. *Epilepsy & Behavior* 2017; 66:105-112.
- Japaridze G., Kasradze S., Lomidze G., Zhizhiashvili L., Kvernadze D., Geladze K., Beniczky S. Focal EEG features and therapeutic response in patients with juvenile absence and myoclonic epilepsy. *Clin Neurophysiol.* 2016 Feb; 127(2):1182-7.
- Kasradze S., Alkhidze M., Lomidze G., Japaridze G., Tsiskaridze A., Zangaladze A. Perspectives of epilepsy surgery in resource poor countries: A study in Georgia. *Acta Neurochirurgica* 2015; 157:1533-1540.
- Maisuradze L. M., Zhizhiashvili L.V., Lomidze G.V., Kasradze S. V. Daytime Sleepiness and epilepsy: A pilot study. *Neurophysiology* 2015; 47(6):478-481.
- Shatirishvili T., Lomidze G., Tatishvili N., Gabunia M, Kipiani T. Short-term outcome and major barriers in the CSE in children: Study in Georgia, *Epileptic Disorders*, 2015; 17(3): 292-298.

Meeting

- ILAE/CEA-GLAE International Caucasian Summer School (2016, Tbilisi).
- International Conference on "Disability and epilepsy" (2016, Tbilisi).
- Discussions about new guidelines, definitions, classifications, reports and recommendations of ILAE – roundtable on the base of Epilepsy Prevention and Control Centre (Institute of Neurology and Neuropsychology and Iashvili pediatric neurology clinic) every month.
- Conferences on new antiepileptic drugs.

Summary of Activities in 2015/16

State Programs

- Prevention and multidisciplinary diagnoses of epilepsy (pediatric/adults) (2005-ongoing)
- Regional programs on drug supply for people with epilepsy after multidisciplinary diagnoses of epilepsy (Pediatric/adults - in Batumi and Achara Region; Kutaisi City Hall, Zestaphoni, Tbilisi City Hall).

Research

Local

- Epidemiology and risk factors of pharmaco-resistant epilepsy in Georgia (2016) (Founded by the Shota Rustaveli National Scientific foundation); Kork Epilepsy Centre
- Sleep disorders in children with epilepsy
- Detrimental effect of utero exposure on antiepileptic drugs on the cognitive functioning in later stages of life (Founded by the Shota Rustaveli National Scientific foundation)
- Validation of the Georgian version of the Neurological Disorders Depression Inventory for Epilepsy (NDDI-E)
- Analyze the data of the Georgian State Program on Epilepsy and a national epilepsy registry (annual)

International

- EURAP
- EpiNet
- EEG-SCORE
- Antiepileptic drug trials (Lacosamide)

Defended Theses

- Epidemiology of Epilepsies in Georgia (2015)
- Quality of life in people with epilepsy living in Georgia (2015)
- Epidemiology and risk factors of pharmaco-resistant epilepsy in Georgia (2016)

Adapted and Developed Standards

- Multidisciplinary (neurologist/epileptologist, neuropsychologist, psychiatrist, standard EEG,



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high resolution MRI) diagnoses for specialized epilepsy center by the National Guidelines and Protocols (pediatric/adults)

- National Epilepsy Registry (since 2005)
- Drug monitoring (all old and new AEDs, some newest AEDs)
- Video-EEG monitoring (since 2014).
- EEG -Telemetry and pre-surgical evaluation for persons with pharmaco-resistant epilepsy (36 cases) (since 2014).
- Epilepsy surgery [in collaboration with professionals from Italy (Roma, Bambino Gesù), Germany (Freiburg, Epilepsy Centre), Turkey (Achibadem Clinic) and USA (Jefferson University, Comprehensive Epilepsy Centre)]

Social events

- “European epilepsy day” (2015, 2016)
- “World Epilepsy Day” in collaboration with patient’s association (2015, 2016) (“Georgian Association of Young Epileptologists” and Epilepsy Prevention and Control Centre).
- TV broadcasts on epilepsy (six in 2015, seven in 2016)
- Radio broadcasts on epilepsy (seven in 2015, three in 2016)

Awards

- ILAE - European Epilepsy Education Award [Prof. Nino (Nana) Tatishvili]

Summary of Activities in Relation to Global Campaign in 2015 and 2016

Educational Program

- Sub-specialty on Electroencephalography and clinical neurophysiology - approved by Georgian MoH (2016).

Guidelines and Protocols

- Guideline on diagnosis and treatment of epilepsy (3rd revision, approved by MoH, 2016)
- Guideline on Status Epilepticus (approved by MoH, 2016)
- Protocol of MRI investigation for adult people with epilepsy (approved by MoH, 2016)
- Protocol of MRI investigation for children with epilepsy (approved by MoH, 2016)
- Protocol for status epilepticus in children/adults (revised and approved by MoH, 2016)
- Protocol for management of generalized epilepsy (approved by MoH, 2016)
- Protocol for presurgical evaluation of people with pharmaco-resistant epilepsy (adapted on the base of INN)

VIREPA-courses

Young physicians were trained on

- Clinical epileptology
- Neurovisualisation
- EEG investigations (basic, clinical –pediatric/adults, sleep-EEG, EEG-score)
- Genetics of epilepsy

Participation in ILAE - Teaching Courses

- San Servolo (2)
- Tagliacozzo (4)
- EILAT (7)
- EPODES (2)
- DSSEE (3)
- Caucasian Summer School (26)

Fellowships

- UCL Institute of Neurology (UK) (3).
- Chalfont epilepsy centre (UK) (2)
- Jefferson Epilepsy Comprehensive centre (USA) (1)
- Sharite epilepsy Centre (DE) (3)
- Danish epilepsy Centre (3)
- SEIN-Epilepsy Centre (NL) (2)
- Kork Epilepsy Centre (DE) (1)
- IRCCS Ospedale Pediatrico Bambino Gesù - SEDE GIANICOLO (Roma, Italy) (5)

Activities in conjunction with local IBE affiliate

- “European Epilepsy Day” (2015, 2016)
- “World Epilepsy Day” (2015, 2016)

In collaboration with “Georgian Association of Young Epileptologists” (Ass. member of IBE) and Epilepsy Prevention and Control Centre at the INN.

Current Officer roster with e-mails

Prof. Nana (Nino) Tatishvili - President
n_tatishvili@hotmail.com

Prof. Tina Geladze - Past President -
n_tatishvili@hotmail.com

Ass. Prof. Sofia Kasradze - Secretary General
sofiakas@gmail.com

Ass. Prof. Maia Jibladze - Vice President
d.tavkhelidze@yahoo.com

Prof. Otari Toidze - Vice President
otoidze@yahoo.com

Georgi Japaridze - Treasurer
gjaparidze58@gmail.com



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Future Plans

2017- Election of new GLAE board

2017-2018

- Held to International Conferences in Georgia
 - a. New Horizons of Epilepsy
 - b. Developmental Disabilities and Epilepsy
- Preparation of intensive teaching course formats for continuing education on epilepsy (adult/pediatric)
- Perfection of Epilepsy Care in Georgia (participation in EuroNASH project)
- Development of new guidelines and protocols
- Development of new Curriculum in Neurology (Chapter Epilepsy) for Medical Schools
- Preparation of Handbook on Epilepsy for medical schools (Georgian)
- Development of epilepsy surgery service in Georgia
- Implementation of Ketogenic Diet service in Georgia
- Development of epilepsy genetic service in collaboration with international Genetic Centers
- Development of treatment and care of Rare Epilepsy Diseases in collaboration with international experts (participation in EpiCARE project).

Officer Election Date

17 March 2017

Report by

Sofia Kasradze, Secretary General of the Georgian League Against Epilepsy

GERMAN SOCIETY FOR EPILEPTOLOGY

Publications

Zeitschrift für Epileptologie

Meeting

53. Jahrestagung der Deutschen Gesellschaft für Epileptologie e.V. in Jena, March 2.-5., 2016

Summary of Activities in 2015/16

The German Chapter of the ILAE (Deutsche Gesellschaft für Epileptologie) was re-established in 1957 (www.dgfe.info). The chapter has been continuously developing, counting 1,483 members in 2016. The mission of the DGfE is to support health care professionals, researchers and patients in the common goal of better understanding and

treating epilepsies. We are also committed to public outreach in an effort to reduce discrimination and stigmatization of patients with epilepsy. Our annual conferences aim to promote scientific exchange and strongly support further education and social networking of our members. In 2016, the meeting was held in Jena, March 2-5. 29 scientific symposia, 19 half-day teaching courses and seminars, as well as other main platform presentations (presidential symposia and industry sponsored symposia). 923 participants discussed the broad spectrum of clinical and experimental epileptology. Mrs. Pfäfflin and Dr. Dennig were awarded with an honorary membership of the DGfE. The "Zeitschrift für Epileptologie" is the official journal to the DGfE (www.zepi.springer.de). The mission of this peer-reviewed journal and their Editors-in-Chief Heidrun Potschka and Bernhard Steinhoff is to offer up-to-date knowledge in the field of clinical epileptology and research to the German speaking community of neurologists and pediatricians with special interest in epileptology. The journal published four issues in 2016. Each issue offered a series of peer-reviewed articles about a main topic, such as epilepsy and music (volume 29 issue 1), genetic testing in epilepsy (volume 29 issue 2), epilepsy surgery (volume 29 issue 3) and epilepsy in public (German-speaking narrative literature, drawing of seizures, print media, television and in National Socialism; volume 29 issue 4). Special sections report news from the DGfE and its commissions and from the Michael Foundation. Questions to the expert, case reports, journal club and book reviews are additional features of the journal. All DGfE society members receive a full subscription to the journal as a member benefit.

Summary of Activities in Relation to Global Campaign in 2015 and 2016

The DGfE recognizes that – as a society in an economically privileged part of the world – it has a duty to try and contribute to improving epilepsy care in developing countries. The DGfE has implemented and financed several international support projects, such as the National Epilepsy Program in Namibia.

Educational Activities

We are committed to education about epilepsy, both amongst the lay public and health care professionals. The German chapter offers a defined curriculum in clinical epileptology for medical doctors, culminating in a Certificate of Epileptology. During the annual conferences, and at additional venues, education for clinicians is supported by the Academy of Education in Epileptology, which was founded in 2004 and provides a wide-ranging course program. The DGfE also supports a number of further measures for training and education in the fields of clinical and basic epileptology, including the Otfried-Foerster Stipends for



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young doctors that enable them to pursue and epilepsy research project. A four day international training course was offered for Neuropathology and Epilepsy Surgery in Erlangen, October 6-9, 2016 (endorsed by the ILAE and International Society of Neuropathology).

Activities in Conjunction with Local IBE Affiliate

DGfE collaborates closely with the patient organization 'Deutsche Epilepsievereinigung e.V.', the German chapter of the International Bureau of Epilepsy (www.epilepsie-vereinigung.de). We jointly organize a patient day at the DGfE Annual Meeting (in Jena on March 5, 2016), as well as the annual German Epilepsy Day (Berlin, October 5, 2016).

Future Plans

The German ILAE chapter is an active society with an ever growing agenda for better clinical care, education and teaching in epileptology. To accomplish all our aims and challenges, DGfE installed 16 ad-hoc commissions (www.dgfe.info). Recently, we have encouraged junior leaders in epileptology to assemble as a commission of young epileptologists (Junge Epileptologen, www.junge-epileptologen.de). With financial support from DGfE, young epileptologists will improve their skills to organize scientific symposia and topic-oriented teaching workshops. The Dieter-Janz-Award of the Peter and Jytte Wolf foundation is specifically devoted to recognizing successful young epileptologists in Germany. Dr. med. Janna Riechmann is the 2016 awardee for her work entitled, "Costs of epilepsy and cost-driving factors in children, adolescents, and their caregivers in Germany". Biannually, all German speaking ILAE chapters (DE, AU, CH) organize a cooperative meeting. In 2017, the annual DGfE meeting will be, therefore, in Vienna, May 3-6.

Officer Election Date

4th March 2016

Report by

Prof. Dr. Ingmar Blumcke

HONDURAN EPILEPSY SOCIETY

Meeting

February 16-18, 2017

Summary of Activities in 2015/16

During the past two years, (2015-2016), the first activity in our society was the election of a new committee, and the results of the election were:

Dr. Arnold Thompson - President

Dr. Humberto Su - Vice President

Dra. Eunice Ramirez - Secretary

Dr. Allan Alvarez - Treasurer

Dr. Amilcar Zelaya - Prosecutor

Dr. Marco Tulio Medina - Vocal

Dr. Lazaro Molina - Vocal

Dr. Luis Cesar Rodriguez - Vocal

Additionally, we have two new members. In this time, we are working in the organization of the Central-American Congress of Neurology. This congress will be taking place in San Pedro Sula (second largest city of Honduras) on February 16-18, 2017. As a part of the activities of our congress, we will have the ALADE Course (Curso de la Academia Latinoamericana de Epilepsia - Latin-American Academy of Epilepsy Course) of the Commission of Latin-American Affairs from the International League Against Epilepsy (ILAE). The next topics will be discussed in the course: Genetic epileptic syndromes in childhood and adolescents, Treatment and prognosis of epileptic syndromes, Pregnancy and epilepsy, Cetogenic diet and epileptic syndromes Cerebro-vascular disease and epilepsy Video-EEG session. The ALADE course is designed for general neurologists and epileptologists, general practitioners, internal medicine, neurosurgeons, nurses and all personnel working in medical services destined to attend to people living with epilepsy. On the other hand, we are working with Societies and other groups to support relatives of people living with epilepsy. In the National Hospital Dr. Mario Catarino Rivas (second largest medical center of Honduras), we have celebrated two consecutive years of the World Epilepsy Day, with medicine students from the National Autonomous University of Honduras - Valle de Sula.

Summary of Activities in Relation to Global Campaign in 2015 and 2016

We are working with societies and other groups to support relatives of people living with epilepsy. In the National Hospital Dr. Mario Catarino Rivas (second largest medical center of Honduras), we have celebrated two consecutive years of the World Epilepsy Day, with medicine students from the National Autonomous University of Honduras - Valle de Sula.

Educational Activities

Central-American Congress of Neurology and ALADE Course.

Activities in Conjunction with Local IBE Affiliate

Promoting education for patients in the two largest medical centers in Honduras, in Tegucigalpa and San Pedro Sula.

Officer Election Date

August, 2015

Report by

Arnold Thompson, MD



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HONG KONG

Publications

1. An update of the Hong Kong Epilepsy Guideline-Part I: consensus statement on the use of antiepileptic drugs in Hong Kong. Hong Kong Medical Journal (in print)
2. An update of the Hong Kong Epilepsy Guideline-Part II: convulsive status epilepticus. Hong Kong Medical Journal (in print)

Meeting

21 Jan 2016, 13-16 May 2016, 6 Jun 2016, 15 Aug 2016, 10 Dec 2016

Summary of Activities in 2015/16

The Hong Kong Epilepsy Society (HKES) is striving to fulfil its role in the advancement and dissemination of knowledge concerning epilepsy. The HKES encourages research in epilepsy and the promotion of prevention, diagnosis, treatment, advocacy and care for persons with epilepsy. The HKES seeks to improve education and training in the field of epilepsy. These objectives were pursued in 2015/16, first with a government-funded program on specialist nursing of epilepsy under the Professional Service Development Assistance Scheme (PSDAS). The project achieved education on specialist nursing and an educational CD was produced for the purpose of promulgating and campaigning for epilepsy nurses. Second, a series of consensus meetings were held between 2015 and 2016, which consolidated four essential aspects of epilepsy care since the publication of the first version of The Hong Kong Epilepsy Guideline in 2009: antiepileptic drugs, status epilepticus, refractory epilepsy, women & epilepsy. Thirdly, as an ongoing community project, the HKES will engage The Hong Kong Rehabilitation Society in a questionnaire on the effect of name-changing of epilepsy.

Summary of Activities in Relation to Global Campaign in 2015 and 2016

Hong Kong hosted the 11th Asian Oceanian Epilepsy Congress between 13th and 16th May 2016. This is the first time the Hong Kong Chapter hosted an ILAE event. During this period, 1053 delegates from 48 countries participated in the congress. The opening ceremony was hosted by Dr Ada Yung, The president of the Hong Kong Epilepsy Society, Dr Ko Wing Man, Secretary for Food and Health Bureau, HKSAR, Dr Shichuo Li and Dr Chen Hong, president(s) of the China Association Against Epilepsy, Prof Byung-In Lee, CAO chair, Prof Emilio Perucca, ILAE president, Denise Chapman, Co-chair of IBE Western Pacific, and Athanasios Covanis, IBE President. Four Asian Oceanian Outstanding Epilepsy Achievement Awards and 10 Golden Light Awards were presented during

this conference. The Masakazu Seino Memorial lecture was given by Prof Akio Ikeda. The featured symposium of the congress included autoimmune encephalitis (chairman's symposium). A total of 531 abstract submissions were received during the conference. Two platform presenters received the Tadokoro award and 25 participants received the bursary from AOEC.

Educational Activities

The 1st quarterly meeting featured Prof Steve Chung from Arizona, USA who lectured the audience on treatment strategies for partial-onset seizure (mono vs polytherapy). The occasion was chaired by Dr Colin Lui and an additional case presented by Dr Eric Yeung. The 2nd quarterly meeting had Dr Vicente Villanueva as the invited speaker. The occasion was chaired by Dr Howan Leung and Dr TL Poon. An additional case was presented by Dr Maggie Yau. The 3rd quarterly meeting featured Ms Ingrid Kan, an experienced dietitian who provided insightful information on ketogenic diet and modified Atkin's diet for epilepsy. The annual scientific meeting was about the clinical impact of modern EEG technique and epilepsy surgery evaluation. The Part II of ASEPA EEG examination was held on the day following the ASM during which time 12 candidates were examined at the Prince of Wales Hospital. The HKES also supported The Hong Kong Neurological Society for a meeting which featured status epilepticus (Prof William Barsan, Dr Jason Fong, Dr Aidan Neligan, Dr Eva Fung, Dr Raymond Lee).

Activities in conjunction with local IBE affiliate

One of the highlights of the 11th AOEC is the Epilepsy and Society Symposium, a series of talks dedicated to patients, family members, and support groups. The Symposium began with addresses from Dr Ko Wing-Man and Athanasios Covanis. Afterwards, there was sharing by Dr Ko and Byung-in Lee about the renaming of epilepsy in the Asian Oceanian region and the International Epilepsy Caring Day by Dr Shichuo Li. Dr Eva Fung from Hong Kong discussed the use of electronic apps on mobile phones. Prof Martin Brodie spoke on specialist nursing and Dr Derrick Chan spoke on collaborative epilepsy care. The finale to the day's event was marked by the performance by a group called "Kids on the Block," which featured a puppet show on epilepsy!

Future Plans

The HKES will take the initiative to continue its role in mitigating stigma among patients with epilepsy. There will be ongoing effort to continue with evaluation of the benefit of name-changing ceremony for epilepsy. The HKES will take the lead in liaising with various professional bodies for a high-standard, pragmatic EEG examination in HK, catered for different audiences including nurses and technical grade personnels.



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HUNGARIAN EPILEPSY LEAGUE – (HEL)

Publications

Official Guideline of Epilepsy Care, by A. Fogarasi, V. Juhos and J. Janszky (eds.). 2016.

Meeting

2015 - EL Section in frame of the 47th Congress of Hungarian Clinical Neurophysiologic Society, 04. 06. – 06. 06., Szeged. - 32th Hungarian Epilepsy Workshop, 29. 10. – 31. 10., Győr.

2016 - 13th Biannual National Congress of HEL, 26. 05. – 28. 05., Szeged. - 33th Hungarian Epilepsy Workshop, 13. 10. – 15. 10., Győr.

Summary of Activities in 2015/16

- Election of Board: Fogarasi, Andras president, Szupera, Zoltan secretary general, Fabo, Daniel president elect, Janszky, Jozsef past president.
- Reevaluation and care of personal HEL qualifications 'Physician Trained in Epilepsy' (PTE) and 'Epilepsy Specialist' (ESP.)
- In agreement of the Hungarian Association of Clinical Neurophysiology, carrying on the creation of a new HEL qualification "EEG license for PTE or ESP".
- As a member of Owners Board participation in editing and publishing of Clinical Neuroscience/ Idegyógyászati Szemle (Idegyogy Sz.)
- The HEL is making great effort in order to renew sporting licence in people with epilepsy, to the Hungarian Society of Sports Medicine.
- The HEL renewed the homepage (epilepszia.hu).

Summary of Activities in Relation to Global Campaign in 2015 and 2016

- Patronizing and supporting the European Epilepsy Day both years on 14 February.
- Publications for patients and their families about epilepsy.

Educational activities

- Teaching courses about modern diagnostic and therapeutic methods in epilepsy.
- The HEL established the Epilepsy Fellowship. It includes a tutorial education and financial support for young epileptologists, under a three years long period. This program started in 2016.

Activities in conjunction with local IBE affiliate

- The Hungarian Association for the Future of People with Epilepsy is member of the IBE since 2007. HEL supported the activity of the organization in providing an umbrella function and coordinating the local societies.
- Patronizing the Purple Day.

Future Plans

- To continue the regular educational courses.
- To elaborate the new standards of the quality control, for epilepsy care in Hungary.

Officer Election Date: 2019

Report by

Fogarasi, Andras (president), Szupera, Zoltan (sec)

INDIAN EPILEPSY SOCIETY

Publications

Epilepsy India & International Journal of Epilepsy

Meeting

Annual

Summary of Activities in 2015/16

- IES-Phenobarbitone Consensus Document: We have already published the IES-Phenobarbitone Consensus Document which was peer reviewed and highly appreciated by Dr. Prof Martin J Brodie, Glasgow, U.K, Dr.(Prof) Patrick Kwan-Melbourne, Australia, Dr. (Prof.) U.K.Misra, Dr. (Prof.) Abraham Kuruvilla and Dr. (Prof) Gagandeep Singh.
- Indian Epilepsy Society- Valproic Acid: Indian Consensus Document: The document was sent for peer review to three International experts and three national experts. i.e Professor Emilio Perucca-Italy, Prof. Lim Shih Hui –Singapore, Prof. K.P. Vinayan –India, Prof. Sangeeta Ravat-India. This consensus document was released on the occasion of the 17th Annual Conference of Indian Epilepsy Association and Indian Epilepsy Society, ECON 2016 at Visakhapatnam.
 - International Journal of Epilepsy (IJEP):
 - The 5th issue January – June 2016 of IJEP is under publication. We are happy to share that IJEP is now indexed in Scopus. We are receiving articles from India's reputed institutions as well as internationally.
 - International Journal of Epilepsy (IJEP) has been listed in Scopus on completion of two years of publication of 1st issue of the Journal.
 - The submission of articles in IJEP has been shifted to a new system called EVISE w.e.f 10th May 2016. This system permits us to submit the articles in an easy way and is quite user friendly.



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Summary of Activities in Relation to Global Campaign in 2015 and 2016

- Asia Oceania Epilepsy Award (AOEC) and Call for Nominations: The name of Dr. Manjari Tripathi was nominated by the Indian Epilepsy Society for Asia Oceania Epilepsy Award and she was selected for the award and received it in Hong Kong during the 11th AOEC (Asia Oceania Epilepsy Congress 2016).
- Samuel Wiebe Elected ILAE President, 2017-2021 term
 - Sam Wiebe was elected with 68% of the eligible votes in the election by ILAE chapter members that concluded 2 May 2016.
 - Out of the 114 Chapters, 83 voted while seven were ineligible owing to not being up to date with their dues. We would urge all 114 Chapters to participate in the next round of the elections, (the nominations for the Executive Committee,) which will commence in late August 2016.

Educational Activities

- IES-Phenobarbitone Consensus Document: We have already published the IES-Phenobarbitone Consensus Document which was peer reviewed and highly appreciated by Dr. Prof Martin J Brodie, Glasgow, U.K, Dr.(Prof) Patrick Kwan-Melborne, Australia, Dr. (Prof.) U.K.Misra, Dr. (Prof.) Abraham Kuruvilla and Dr. (Prof) Gagandeep Singh.
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 - The submission of articles in IJEP has been shifted to a new system called EVISE w.e.f 10th May 2016. This system permits us to submit the articles in an easy way and is quite user friendly.

Future Plans

EEG Workshops ASEPA Examination Epilepsy School

Report by

Secretary General

INDONESIA LEAGUE AGAINST EPILEPSY

Summary of Activities in 2015/16

- We have been elected a national officer in August 2015.
- We organized some academic activities in conjunction with ASEPA and local branches.
- We have completed preparation of a book of epilepsy guidelines for general practitioners
- We celebrate Epilepsy Day every February, in conjunction with the local IBE.

Summary of Activities in Relation to Global Campaign in 2015 and 2016

In these last two years, we have promoted a greater understanding about epilepsy to everybody through public seminars, radio, newspapers, etc.

Educational Activities

Biennial National Epilepsy Meeting, August 2015
Epilepsy Summer Course, August 2016. Some epilepsy symposia in conjunction with a regional neurological group. EEG courses for neurologists and technicians in some regional neurological groups. Completed preparation of a book of Epilepsy Guidelines for General Practitioners.

Activities in Conjunction with Local IBE Affiliate

The League celebrated Epilepsy Day in February 2015 and 2016 in every branch.

Future Plans

- As Host of 12th AOEC in Bali on June 2018
- Hold an Epilepsy Summer Course in Mataram Lombok on May 2017
- Promote collaborative efforts with national insurance about the availability of AEDs and procurement of new AEDs

Report by

Kurnia Kusumastuti and Diah Kurnia Mirawati



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IRAQI LEAGUE AGAINST EPILEPSY IQLAE

Meeting

2nd December 2016

Summary of Activities in 2015/16

- Conference of IqLAE on Friday 2nd of December 2016 in Baghdad (Eyon Baghdad Restaurant); a group of lectures were presented and discussed. Among them: Epilepsy Comorbidity, Presurgical Evaluation, Epilepsy Surgery and Promotion about Lacosamide.
- Symposium of Iraqi Chapter IqLAE on the event of International Day of Epilepsy (8 Feb 2016) at Eyon Baghdad Restaurant was held on the nearest Friday after the 2nd Monday of Feb (the event).
- Symposium of IqLAE on 26th of Nov 2015 held on Friday at Eyon Baghdad Restaurant;
- Conference of IqLAE on June 2015 held Friday at Eyon Baghdad Restaurant; the main topics were about the new definition of epilepsy and new classification.
- Symposium of IqLAE on 19th of FEB 2015 held at The Central Child Hospital in Baghdad; the main topic was: The Role of EEG in Misdiagnosis and in Classification of Epilepsy.
- Attendance and Participation in Baghdad Medical College Annual Conference.
- Attendance and participation in the Annual Conference of Iraqi Neurology Association.
- Attendance and participation in the Annual Conference of AlKufa College of Medicine.

Summary of Activities in Relation to Global Campaign in 2015 and 2016

- Attendance and participation in 12th European Conference of Epileptology, Prague 11-15 Sep 2016.
- Attendance and participation at the 3rd Conference of Jordanian Chapter Against Epilepsy in Amman in Oct 2015.
- Attendance of CEMA/ILAE Conference Commission of eastern Mediterranean Affairs held in Dubai 2016.
- Attendance at a group of conferences in the region and in Europe.

Educational Activities

- Monthly lectures on EEG and epileptology presented regularly at Baghdad Teaching Hospital.
- Weekly meetings at the Epilepsy Clinic with discussions of clinical cases with students and colleagues.

Future Plans

- Symposium of IqLAE on 27th of Jan 2017 held at Eyon Baghdad Restaurant in the memory of the International Day of Epilepsy 2017 (the 2nd Monday of Feb).
- The First Asian Master Class Conference on 2-4 of March 2017 held at Babylon Hotel in Baghdad (regulated and arranged by IqLAE with Ministry of Health).
- Attendance and participation of the CEMA/ILAE Conference at Luxor-Egypt on 16-18th Feb 2017.

Officer Election Date

Spring 2017

Report by

Ghaieb Aljandeel/Vice President IqLAE

ITALIAN LEAGUE AGAINST EPILEPSY (LICE - LEGA ITALIANA CONTRO L'EPILESSIA)

Summary of Activities in 2015/16

Our history:

The Italian League Against Epilepsy is a scientific society with the statutory objective of contributing to the treatment and assistance of patients with epilepsy and to their integration into society at large, by promoting and pursuing all kinds of activities designed to achieve those aims.

The League was set up for the first time in Milan in 1955 during the meeting called by Mario Gozzano and Eugenio Medea, who became President and Vice President respectively, while Raffaello Vizioli was appointed Secretary. After a temporary loss of vigour and pace, the Italian League Against Epilepsy was founded anew in 1972, with Lugaresi as President and Canger as Secretary.

From then onwards, Lugaresi was succeeded by Angeleri, Tassinari, Mutani, Avanzini, Canger, dalla Bernardina, Munari, Vigevano, Perucca, Tinuper, Beghi, Michelucci and Capovilla, and under each developed into one of the most dynamic, close-knit Italian scientific bodies, consistently working to implement numerous activities aimed at responding to the League's institutional aims. The LICE is currently composed of 800 members, neurologists, child neuropsychiatrists, neurosurgeons, neuropsychologists, etc., who operate throughout Italy, dealing mainly or exclusively with the diagnosis and treatment of epilepsy.



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Aims

LICE strives to:

- promote research into the causes of and treatments for epilepsy.
- collect and process statistical data and information on a national and regional basis.
- promote and encourage the setting up of centres for the diagnosis and treatment of patients with epilepsy.
- establish and maintain relations with the ILAE and with national associations and entities dealing with the treatment and assistance of people with epilepsy.
- organise congresses, scientific and informative conferences on the medical and social aspects of the disease, and organise national scientific meetings at least once a year.
- establish and maintain relations with the pertinent national and regional bodies to promote legislation and measures to help people with epilepsy.
- collect contributions and donations and organise fundraising for the purpose of achieving the statutory objectives.

The contribution of Italian epileptologists to the advancement of the scientific knowledge in epilepsy is substantial. A MEDLINE search of the articles on epilepsy published by Italian scientists showed more than 4,000 titles. Italian researchers are actively involved in several commissions of the International League Against Epilepsy (ILAE).

Meeting

National Congress

The National Congress of LICE is organized yearly in June, and is attended by no fewer than 450 neurologists, child neurologists, and neurosurgeons, many of them younger than 40 years of age.

The Congress deals with a different topic each year, but there is ample time set aside for free discussion of other issues. During the Congress, each Commission and Study Group reports on the progress of the projects underway and puts forwards proposals for new research.

In 2015, the National Congress has been held in Genova on 10-12 June; the main topic was "Nonepileptic Paroxysmal Events".

In 2016 it was held in Rome on 8-10 June and the main topic was "The physician in front of drugs' options: The new therapeutic strategy".

Multi-Site Meeting on Epileptology

The Multi-Site Meeting on Epileptology is held every year in January, at La Sapienza University of Rome, with some 350 epileptologists taking part, most of them young (29-30 January 2015; 28-29 January

2016). During the event, discussion takes place on over 50 clinical cases that are challenging to diagnose, and treatment. The discussions are divided into specific sessions: genetic aspects; children and adult controversies; particular aspects of neurophysiological and neuroimaging; neurosurgery.

Video-EEG Course

The Residential Course on VEEG was held on 2-5 October 2016 at Bellaria Hospital in Bologna. Some 40 young physicians from all over Italy have attended this course.

Local Meeting

Several regional meetings and workshops took place all around Italy in 2015 and 2016, arranged by the local LICE coordinators.

Promotional and Educational Activities

The Commission for Promotional and Educational Activities of LICE has organized in 2015 and 2016 national campaigns aimed at raising awareness of epilepsy, among both the general population and specific groups (i.e. teachers).

The promotional activities have been especially arranged in occasion of the National Epilepsy Day held on 3 May 2015.

As of 2016, National Epilepsy Day has been aligned to the IBE-ILAE International Day (8 February 2016). The website www.lice.it provides the list of the activities and projects to raise awareness of epilepsy issues among the general public in Italy. The activities are updated annually and implemented by the Epilepsy LICE Foundation.

The Epilepsy LICE Foundation is a no-profit Foundation seeks to support scientific research into epileptic diseases and related conditions. The Foundation's main aim is to organize fundraising activities to support specific research projects. In 2015, funds were assigned for carrying out two research projects regarding genetic aspects of epilepsy. A new assignment has been arranged in 2016 on the same research field.

IVORY COAST: THE IVORIAN LEAGUE AGAINST EPILEPSY/ ASSOCIATION IVOIRIENNE DE LUTTE CONTRE L'EPILEPSIE

Summary of Activities in 2015/16

The Ivorian League Against Epilepsy had a few activities during this last two years, consisting of education of specific groups of caregivers and sensitization of general population.



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Summary of Activities in Relation to Global Campaign in 2015 and 2016

1. April 2015: Radio broadcast on local radios. Program: Health for all. Theme: Understanding epilepsy.
2. April 2015: Awareness program on a national television channel.
3. October 2015: sensitization of the general population of Bouaké, the second largest town in Côte d'Ivoire.

Educational Activities

1. May 2015: Paediatricians training day about diagnosis and management of epilepsies (2nd edition) in Abidjan.
2. October 2015: Education of general practitioners and nurses on diagnosis and management of epilepsies in Bouaké.
3. October 2016: Training day of nurses of Bouaké in epilepsy management.

Future Plans

- Revitalize the local association of professionals and the parents of epileptics.
- Resume national epilepsy days.
- Continue the training of paediatricians, general practitioners and nurses in Abidjan and in provincial towns.

Officer Election Date

May 29, 2012

Report by

Ange-Eric KOUAME-ASSOUAN

JAPAN EPILEPSY SOCIETY

Publications

Journal of the Japan Epilepsy Society

Meeting

49th annual meeting of the Japan Epilepsy Society,
50th annual meeting of the Japan Epilepsy Society

Summary of Activities in 2015/16

1. The number of members has continuously increased to 2,356 as of Dec 1st, 2016. Over 90% of them are doctors, majority of them are pediatricians, rest are psychiatrists, neurologists, and neurosurgeons with almost same ratio. Makiko Osawa was reappointed as the President and Akio Ikeda, Kensuke Kawai and Nobukazu Nakasato were approved as Vice President with

approval from all Board members at reelection back in 2015. The Election Commission and the Vagus Nerve Stimulation Committee were newly established.

2. Through lobbying campaign WHO collaborated with International ILE and IBE, and a resolution was made at 68th WHO General Assembly held on May 26th, 2015. Japan Epilepsy Society should take variety of measures/actions for enlightenment in the next 10 years. In accordance with the resolution, some approaches by Japan Epilepsy Society were made to the Japanese Government and Japanese people in 2016.
3. In commemoration of the 50th anniversary meeting, the epilepsy white paper and commemorative publication was issued in 2016.

Summary of Activities in Relation to Global Campaign in 2015 and 2016

The lecture presentation was given in commemoration of "International Epilepsy Day" at Tokyo on Feb 2 2016. Makiko Osawa gave a presentation about Epilepsy and Keiji Suzuki, Chairman of Japanese Bureau for Epilepsy, gave an overview speech about the understanding of epilepsy.

Educational Activities

"Journal of the Japan Epilepsy Society" was published three times and the electronic journal "Epilepsy & Seizure" was issued as well.

The 49th Annual Meeting of the Japan Epilepsy Society was held at Nagasaki city in Oct. 2015 with 1,200 participants, chaired by Hiroshi Baba.

The theme was "Today is the Future and the Future is All Yours".

The 50th Annual Meeting of the Japan Epilepsy Society was held at Shizuoka city in Oct 2016 with 1,400 participants, chaired by Yushi Inoue.

The theme was "Science and art of epilepsy".

Activities in Conjunction with Local IBE Affiliate

The exhibition of "International Epilepsy Day" was held with collaboration of Japanese Bureau for Epilepsy.

Media seminars were given at times and lectures were dispatched to the Annual Meeting of Japanese Bureau for Epilepsy.

Future Plans

In accordance with the white paper issued in 2016, tasks regarding to medical care, welfare and administration will be carried out.

The 51st Annual Meeting of the Japan Epilepsy Society, chaired by Akio Ikeda, will be held at Kyoto city on Nov 3rd to 5th 2017.



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52nd Annual Meeting of the Japan Epilepsy Society, chaired by Hitoshi Yamamoto, will be held at Yokohama city on Oct 25th to 27th 2018.

Officer Election Date
Nov 2nd, 2017

Report by
Masako Watanabe

KENYA SOCIETY FOR EPILEPSY

Publications
Five in 2016

Meeting
Every month (except December and January)

Summary of Activities in 2015/16
The KSE was involved in several training seminars for physicians and field health operatives (nurses, community workers, etc). These seminars were held in Nairobi every month and quarterly in a County capital. So far, we covered 12 out of 47 capital towns.

Summary of Activities in Relation to Global Campaign in 2015 and 2016
KSE has held several educational caravans for public education and coupled with the professional CMEs (continuing medical education) mentioned above.

Educational Activities
Monthly CMEs in Nairobi and quarterly whole-day seminars in County capitals and Nairobi.

Activities in Conjunction with Local IBE Affiliate
The campaign out in the field is conducted with the official IBE affiliate in Kenya (KAWE) together with at least six other NGOs and CBOs that are stakeholders in Epilepsy through the National Epilepsy Coordination Committee. These latter stakeholders are particularly active in youth and mass mobilization through peer education and dramatization of epilepsy in song and dance.

Future Plans
To take the education and popularisation campaign to all Counties. Ensure we have at least one epilepsy trained health professional in every County and a liaison person in every County. Get an optimal epilepsy data collection from every health facility.

Officer Election Date
August 2017

Report by
Paul G. Kioy

KOSOVO: ASSOCIATION AGAINST EPILEPSY OF KOSOVO

Meeting
Two meetings were held.

Summary of Activities in 2015/16

- We organized activities for European Epilepsy Day (February 9, 2015 and February 8, 2016)
- We held two professional meetings:
The First, May 2015, focused on Electroencephalography.
The second, held in November 2016, focused on refractory epilepsy.

We continued our educational activities through written and audio-visual media.

Educational Activities
The Association provides talks with healthcare professionals on epilepsy, also with patients and their families.

Activities in Conjunction with Local IBE Affiliate
No activities of local IBE affiliates have been recognized for years.

Future Plans
Our plans are to promote epilepsy awareness, and cooperate with all institutions led by the Ministry of Health to raise awareness of professionals, patients, families, and community in general regarding epilepsy.

Report by
Valbona Govori

KUWAIT LEAGUE AGAINST EPILEPSY

Meeting
Kuwaiti-Lebanese Conference

Summary of Activities in 2015/16
Semi-Regular scientific meeting for healthcare professionals dealing with epilepsy in Kuwait. Public awareness activities.



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Summary of Activities in Relation to Global Campaign in 2015 and 2016

1. Multiple single talks/presentations to general physicians and GPs on epilepsy, Status Epilepticus, averaging 3-4 per year.
2. Multiple TV, Newspapers and Radio interviews on the topic of Epilepsy for public awareness, averaging 3-4 per year.
3. Purple Day Celebration: April 11, 2015
4. Purple Day Celebration: March, 2016

Educational Activities

1. 4th Kuwaiti-Lebanese Conference, 31st Jan. 2015, Beirut, Lebanon: Evidence based treatment of status epilepticus from pre-hospital treatment to the treatment of super refractory status.
2. 5th Kuwaiti-Lebanese Conference, 10-11th Apr. 2015, Kuwait: EEG in clinical practice.
3. 6th Kuwaiti-Lebanese Conference, 16th Jan. 2016, Beirut, Lebanon: Cerebrovascular disorders with epilepsy.
4. 7th Kuwaiti-Lebanese Conference, 7th May. 2016, Kuwait: Evidence Based Treatment of Status Epilepticus From pre-hospital treatment to the treatment of super refractory status.
5. April 11, 2016, Epilepsy surgery symposium: Experience from cases done in Kuwait.
6. 27/10/2015, Insights into Status Epilepticus management symposium.
7. 22/12/2015, Epileptic encephalopathy: from infancy to childhood meeting.

Activities in conjunction with local IBE affiliate
No IBE chapter is available in Kuwait, yet.

Future Plans

Regional epilepsy meeting
Regular education activity
Increase awareness campaigns for the Public
Officer Election Date: Feb 1st, 2019

Report by

Abdulaziz Ashkanani, KLAE President

LATVIAN LEAGUE AGAINST EPILEPSY

Meeting

11 May 2015

Summary of Activities in 2011 and 2012

Three national meetings organized. 9th Baltic sea summer school on epilepsy hosted. Video EEG monitoring for children started and reimbursement

improved. Application made to increase number of reimbursed medication.

Summary of Activities in Relation to Global Campaign in 2015 and 2016

Opposition to "stop vivisection" initiative supported by contacting Latvian EU deputies.

Educational Activities

Three national meetings organized. 9th Baltic Sea Summer School on Epilepsy hosted.

Activities in Conjunction with Local IBE Affiliate

There is no functioning local IBE chapter.

Future Plans

Continue to organize national meetings. Build web page to spread information for professionals and patients. Apply for VNS reimbursement. Build epilepsy surgery program.

Officer Election Date

Nov 2017

Report by

Jurgis Strautmanis

MOLDAVIAN LEAGUE AGAINST EPILEPSY

Publications

Nine articles were published in 2016 on topics related to epilepsy.

Meeting

Annual Meeting of the MLAE has been held in October 2016.

Summary of Activities in 2015/16

The Chapter established the National Centre of Epileptology with the following structure:

- Organizational-Coordiative Department
- Outpatient Consultative Department
- Department of Psycho-Social Support
- Neurophysiological Department
- Epileptology Inpatient Department

The National Centre of Epileptology is a participant of the Global Audit of Refractory Status Epilepticus study, Acad. Stanislav Groppa is a member of the International Steering Committee of the Global Audit of Refractory Status Epilepticus. In conjunction with the Ministry of Health of Moldova, two national diagnostic



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and treatment protocols have been approved and implemented in the clinical activity: Epilepsy in Adults and Status Epilepticus. The protocols were elaborated according to ILAE guidelines and resources. There is a clinical study in progress led by Acad. Stanislav Groppa with the topic "Pharmacoresistant Epilepsy: The risk factors, the aspects of clinical, neuroimaging, neurophysiological polymorphism and their role in presurgical assessment".

We also implemented ESI (Electrical Source Imaging) in order to determine the localization of the epileptogenic zone, which is an important tool for presurgical assessment of patients with pharmacoresistant Epilepsy. The special MRI protocol of examination of an epileptic patient has been implemented in clinical activity in collaboration with Prof. Jorg Wellmer from Bochum, Germany.

The members of the Chapter participated in different international and national congresses, conferences and workshops such as:

2nd Congress of the European Academy of Neurology, Copenhagen, Denmark;

12th European Congress on Epileptology, Prague, Czech Republic;

XXIV National Conference of the Romanian Society Against Epilepsy, Bucharest, Romania;

VII International Forum of Epileptologists of the CIS/EURASEC "Epileptology and Paroxysmal States" Sochi, Russian Federation;

RoNeuro Brain Days, 6th European Teaching Course on Neurorehabilitation, Cluj-Napoca, Romania;

Conference: The Days of State University of Medicine and Pharmacy "Nicolae Testemitanu", Chisinau, Moldova;

Annual Conference of Young Specialists of Emergency Medicine Institute, Chisinau, Moldova and presented the following communications:

1. CATERENIUC D. Clinical case "Pseudo-pharmacoresistant Epilepsy." XXIV National Conference of the Romanian Society Against Epilepsy, Bucharest, Romania, 17-19 November, 2016.
2. CHIOSA V. Clinical case "MRI-negative pharmacoresistant Epilepsy". XXIV National Conference of the Romanian Society Against Epilepsy, Bucharest, Romania, 17-19 November, 2016.
3. CIOLAC D., CHIOSA V., GROPPA SA. Epilepsy as a dynamic disorder of neural networks. RoNeuro Brain Days, 6th European Teaching Course on Neurorehabilitation, Cluj-Napoca, Romania, 1-3 June, 2016.

4. GROPPA SA. "Pharmacoresistant Epilepsy: Definition, risk factors, clinical and instrumental evolutive aspects." XXIV National Conference of the Romanian Society Against Epilepsy, Bucharest, Romania, 17-19 November, 2016.
5. MUNTEANU C. Clinical case "Complications of pharmacoresistant epilepsy. Refractory status epilepticus." XXIV National Conference of the Romanian Society Against Epilepsy, Bucharest, Romania, 17-19 November, 2016.
6. STOIANOV N. Clinical case "Structural epilepsy as a result of cerebral heterotopia." XXIV National Conference of the Romanian Society Against Epilepsy, Bucharest, Romania, 17-19 November, 2016.
7. GROPPA SA. Status Epilepticus. Classification, clinical manifestation, and treatment. VII International Forum of Epileptologists of the CIS/EURASEC "Epileptology and Paroxysmal States" Sochi, Russian Federation, 7-8 October, 2016.
8. CATERENIUC D. Genetic Epilepsy. Genetic and phenotype implications. Conference. The Days of State University of Medicine and Pharmacy "Nicolae Testemitanu", Chisinau, Moldova, 20 October 2016.
9. MUNTEANU C. Status epilepticus in intensive care unit – frequency, management, and outcome.

Annual Conference of Young Specialists of Emergency Medicine Institute, Chişinău, Moldova, 20 May 2016. Nine articles were published in 2016 on epilepsy topics as follows:

1. CHIOSA V., CIOLAC D., VATAMAN A., GROPPA SA. Features of presurgical assessment of patients with pharmacoresistant Epilepsy. In: Archives of the Balkan medical union. 2016; 51, 1(supl.1):195-199, ISSN 0041-6940.
2. GROPPA SA., GLAVAN A., GLAVAN D. Social stigma and its impact on quality of life in epilepsy. In: Journal of Academy of Sciences of Moldova, Medical sciences, Nr. 3, Chisinau, R. Moldova 2016.
3. CATERENIUC D., GLAVAN D., GROPPA SA. Pseudo-pharmacoresistant epilepsy. In: Abstract book of XXIV National Conference of the Romanian Society Against Epilepsy, Bucharest, Romania, 17-19 November, 2016, page 27-28.
4. CIOLAC D., CHIOSA V., GROPPA SA. Epilepsy as a dynamic disorder of neural networks. RoNeuro Brain Days, In: Abstract book of the 6th European Teaching Course on Neurorehabilitation, 1-3 June, 2016, Cluj-Napoca, Romania, 2016: 28 (ISSN 2501-7039).



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5. CIOLAC D., CHIOSA V., MUNTEANU C., MIȘINA L., VATAMAN A., GORINCIOI N., GROPPA SA. The importance of dense array EEG in detection of interictal epileptiform discharges and localization of epileptogenic foci. In: Abstract book of the European Journal of Neurology. 2016; 23 (supl.1):152 (ISSN 1351-5101).
6. GORINCIOI N., GROPPA SA. Structural epilepsy as a result of persistent parasitic lesions. In: Abstract book of XXIV National Conference of the Romanian Society Against Epilepsy, Bucharest, Romania, 17-19 November, 2016, page 27-28.
7. MUNTEANU C., GROPPA SA. Status epilepticus in intensive care unit: frequency, management and outcome impact – retrospective study. In: Abstract book of the European Journal of Neurology. 2016; 23 (supl.1):525 (ISSN 1351-5101).
8. MUNTEANU C., Complications of pharmacoresistant epilepsy. Refractory status epilepticus. In: Abstract book of XXIV National Conference of the Romanian Society Against Epilepsy, Bucharest, Romania, 17-19 November, 2016, page 27-28.
9. STOIANOV N., VATAMAN A., GROPPA SA. Structural epilepsy as a result of cerebral heterotopia. In: Abstract book of XXIV National Conference of the Romanian Society Against Epilepsy, Bucharest, Romania, 17-19 November, 2016, page 27-28.

Our members presented three posters on epilepsy topics at international congresses:

1. CIOLAC D., CHIOSA V., MUNTEANU C., MIȘINA L., VATAMAN A., GORINCIOI N., GROPPA SA. The importance of dense array EEG in detection of interictal epileptiform discharges and localization of epileptogenic foci. 2nd Congress of the European Academy of Neurology, Copenhagen, Denmark, 28 -31 mai, 2016.
2. CIOLAC D., KOIRALA N., MUTHURAMAN M., CHIOSA V., MUNTEANU C., VATAMAN A., GROPPA S., GROPPA SA. Bilateral thalamic volume loss in patients with pharmacoresistant temporal lobe epilepsy with and without hippocampal sclerosis. 12th European Congress on Epileptology, Prague, Czech Republic, 11 – 15 September, 2016.
3. MUNTEANU C., GROPPA SA. Status epilepticus in intensive care unit: Frequency, management and outcome impact – retrospective study. 2nd Congress of the European Academy of Neurology, Copenhagen, Denmark, 28 -31 May, 2016.

Summary of Activities in Relation to Global Campaign in 2015 and 2016

In conjunction with the Ministry of Health of Moldova, the list of compensated AEDs which are distributed free

of charge to epileptic patients has been modified and approved. The members of the Chapter participated in media interviews on TV and radio to discuss the epilepsy topic.

Educational Activities

Together with the State University of Medicine and Pharmacy “Nicolae Testemitanu”, the Chapter has developed and conducted a two-week training course in epilepsy as part of postgraduate education for neurologists and residents. Such trainings will be conducted on a regular basis. Many thanks to Prof. Jorg Wellmer, for his kind support in the collaboration with the German Epileptology Centre, and the arranged scholarship in Epileptology for Moldovan neurologists.

Future Plans

Establishment of a National Register on epilepsy with creation of a national computer database. Analyses of the data on pharmacoresistant Epilepsy in Moldova with prospective provision of elected patients with neurosurgery. Organization of monthly clinical-imaging conferences on epilepsy topics. Organization in Moldova of a neurosurgical service for epilepsy. Reactivation of the community education and scholarships for residents who perform research in epilepsy.

Officer Election Date

October 2015

Report by

Dr. Ion Cernocan

MYANMAR: EPILEPSY SPECIAL INTEREST GROUP OF MYANMAR

Meeting

Executive members' meeting every (4-6) months, Annual Meeting

Summary of Activities in 2011 and 2012

- Participating and assisting in the activities of Myanmar Epilepsy Initiative that has been the collaborative project between the Ministry of Health and Sports, Myanmar and WHO since 2013
- Training on convulsive epilepsy to primary health care providers (medical officers, basic health staff and voluntary health workers) from three townships in 2015 and two townships in 2016
- Epilepsy Training of the Trainers and Supervisors (ToTS) for general physicians, neurologists, paediatricians and psychiatrists in 2015



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- Workshop on “Development of National Care Plan for Epilepsy” in 2016
- Monitoring and evaluation in project township areas every month. Adult Epilepsy clinic on every Friday in Yangon. General Hospital Paediatric Epilepsy and Outreach clinics in Yangon Children Hospital and other hospitals of Yangon

Summary of Activities in Relation to Global Campaign in 2015 and 2016

International Epilepsy Day, Yangon in 2015 and Kawmhu in 2016

Educational Activities

- International Paediatric Epilepsy Training (iPET) in collaboration with British Paediatric Neurology Association (BPNA) every year in Yangon Children Hospital
- CME programme on epilepsy for general practitioners and specialists every year

Future Plans

- Epilepsy training in collaboration with Taiwan Epilepsy Association, on (11-02-2017) and (12-02-2017) in Yangon Children Hospital
- Training of primary health care providers in two new townships
- Refresher courses in five old townships of the project
- Development of National Guidelines for Epilepsy
- Launching of National Care Plan for Epilepsy

Officer Election Date

Current EC members were elected at the Annual Meeting in September 2015.

Report by
Nyan Tun

NETHERLANDS: DUTCH LEAGUE AGAINST EPILEPSY

Summary of Activities in 2015/16

The Dutch Liga has about 430 members. Board meetings are four times a year. In 2015 and 2016, the following items were addressed:

- To develop a Dutch Epilepsy Net, i.e. a network in which medical and allied health professionals are collaborating to provide the best possible care for epilepsy patients. Initiators of this project are Cees van Donselaar, neurologist, Rotterdam, and Anton de Louw, neurologist, epilepsy centre Kempenhaeghe, Heeze and Chairman of the Dutch Liga.

- A statement was made that there is insufficient evidence to support the use of cannabinoids in the treatment of (paediatric) epilepsy. The potential for adverse effects was stressed. The results of two studies of the use of cannabis in Lennox- Gastaut and Dravet syndrome are awaited in 2017.
- The Dutch Liga coordinates activities of various working groups, such as the Section of Scientific Research, the Vagal Nerve Stimulation group, Epilepsy Education, Association of Physicians for Patients with a Mental Handicap and the Child Neurology Association.
- Some other issues were - Various questions concerning epilepsy from the Dutch Association of Neurology - A Dutch guideline for Dravet syndrome in children and adults - SUDEP - Valproate prescription in girls and young females - Driving licences and epilepsy

Educational Activities

In June 2016, a National Epilepsy Symposium was organised by the Dutch Liga, in cooperation with the Epilepsy Foundation and the working group of epilepsy specialist nurses. Main topics were post-stroke epilepsy, epilepsy and mental retardation, epilepsy in patients with a brain tumour, transition of care in adolescent epilepsy patients and detection methods of seizures at night.

Future Plans

To develop a Dutch Epilepsy Network

Report by

G.Hageman, MD, PhD, neurologist

NEW ZEALAND LEAGUE AGAINST EPILEPSY

Summary of Activities in 2015/16

In 2016, the NZLAE continued to move forward towards its strategic goals. The predominant activities for the year revolved around work on New Zealand paediatric epilepsy guidelines, education and advocacy.

Summary of Activities in Relation to Global Campaign in 2015 and 2016

New Zealand Paediatric Epilepsy Guidelines are being developed in conjunction with the New Zealand Ministry of Health Complex Epilepsy National Service Improvement Project and the Paediatric Society of New Zealand Clinical Network for Paediatric Neurology. These guidelines have been through a wide consultation process in 2016 and will be



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finalized in 2017. The guidelines will be released with the introduction of the British Paediatric Neurology Association (BPNA) Paediatric Epilepsy Training (PET) courses in New Zealand in May 2017.

The NZLAE has been working closely with the NZ Accident Compensation Corporation to develop an appropriate tool kit for women on AEDs which will be implemented in 2017.

Educational Activities

At the end of 2015, the NZLAE held an educational meeting as a satellite of the New Zealand Paediatric Society Meeting in Wellington. The 2.5-hour session was well attended by the paediatricians and the feedback was positive. The title of the symposium was "Epilepsy Update for Paediatricians – What is hot, what is important and what you need to know in 2015" and covered updates on Epilepsy Genetics and SUDEP.

We also held a NZLAE study day in Oct 2016 in Wellington. This had a particular focus on the nursing management of epilepsy, new onset epilepsy and status epilepticus. This was well attended by a wide range of health care practitioners from throughout New Zealand.

The NZLAE sponsored a project entitled "Epilepsy Teaching Within the New Zealand Undergraduate Medical Curriculum and Epilepsy Research in New Zealand Over the Last Decade". This project found that there is variability in the breadth of epilepsy topics taught, the depth of coverage of these topics and the time allocated to epilepsy teaching between New Zealand medical schools. It provided the NZLAE with baseline information regarding undergraduate epilepsy education and epilepsy research being performed in New Zealand. Using a modified Delphi methodology, we have begun the process of determining an agreed upon core epilepsy undergraduate curriculum which will help us develop e-learning tools for teaching epilepsy to undergraduates at New Zealand medical schools.

Activities in Conjunction with Local IBE Affiliate

The NZLAE is aiming to have a more structured relationship with Epilepsy New Zealand (ENZ) with regards to their staff's professional development. To this end, NZLAE members have volunteered to participate in teaching using video-conferencing. Several pilot teaching sessions have been completed this year and more formal regular delivery of teaching will hopefully be in place for the 2017 year.

Future Plans

2017 will be an exciting year for the NZLAE. In addition to our regular educational meetings we hold each year, we will be introducing PET courses, publishing New Zealand Paediatric Epilepsy Guidelines and developing a tool kit for women on AEDs.

Report by

Lynette Sadleir, President

NIGERIA NATIONAL CHAPTER OF ILAE

The Association held its 2016 Annual General and Scientific Meeting in Lagos, Nigeria in November with the theme Synergy in Neurosciences with emphasis on epilepsy. It was well attended by neurologists, EEG technologists and epilepsy advocacy groups. Part of the activities carried during the three-day conference was the training of EEG technicians and non-doctors on how to give basic life support to patients. Various scientific papers were made on epilepsy and how to improve epilepsy care and awareness in the community. We also discussed methods and ways to improve advocacy especially to politicians, religious and opinion leaders, as well as the entire community with the view of bringing epilepsy and issues bordering on epilepsy to fore in Nigeria. NLAE is putting in place the machinery on how to regulate the practice of electroencephalogram care in the country. This is aimed at standardizing the EEG practice and reporting in order to eradicate quackery. We are hoping that in early in 2017 we should organize short time courses and schools on epilepsy care and EEG training in partnership with international groups for young neurologists, Nurses and EEG technicians.

The group activities also included activities by some affiliated non-governmental groups. These groups work with us as our members, providing medical consultations and advice for them.

Notable among them are the Angiepilepsy Foundation and the CARE Epilepsy Foundation (CAREF). The Angiepilepsy Foundation held numerous road shows at various cities and states in the countries. These activities were graced by top government and religious dignitaries. Presently the group has reached out to more than 4,000 epilepsy patients. These patients and their care givers were educated, started on treatment and referred to the nearest government institutions. The CAREF group carried out two rural outreaches within this time. The group is headed by our President Dr Ezeala-Adikabe Birinus, and focuses more on a rural setting. The group was able to reach out to close to 100 patients who were treated and currently being followed up. The association of EEG technicians, which is an affiliate member of our League, also carried our numerous road shows in Lagos creating awareness for epilepsy. The group was able to create contact with officials from the Lagos State government during this period. We hope that these contacts and road shows will lead to greater funding for epilepsy care at least in children.

Within the year under review some neurologists were trained and certified by the West African College of Physicians and the National Postgraduate Medical



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College of Nigeria. This has increased the number of neurologists in the country and we believe some will play active roles in epilepsy care and advocacy.

Within the same period, the Association lost one of our most active members, Dr Molokwu Orakwue. Dr Orakwue played active roles during his training in epilepsy care in South East Nigeria and in the country as a whole. He will be greatly missed.

NORWEGIAN LEAGUE AGAINST EPILEPSY

Summary of Activities in 2015/16

In both 2015 and 2016, we had a conference, the theme of which highlighted risks of epilepsy and the newly diagnosed epilepsy patients. We also had a video seminar on diagnosis and differential diagnosis of epileptic seizures. We had great support and good discussions.

Summary of Activities in Relation to Global Campaign in 2015 and 2016

Norwegian representation (Kristin Alfstad and Oliver Henning) at the ILAE meeting in conjunction with the International Epilepsy Congress in Istanbul. The Norwegian Chapter has cooperated with the ILAE regarding epilepsy as a global challenge, focusing on lobbying. The aim is to shed light on the recognition of epilepsy as a treatment and societal challenge.

Future Plans

In 2017, we will have a conference, the theme of which is the treatment-resistant patient, and a meeting on treatment with cannabis.

Report by

Anne-Karin Hagen, Secretary

PAKISTAN: EPILEPSY ASSOCIATION OF PAKISTAN

Summary of Activities in 2015/16

1. Holistic management of patients with epilepsy
2. Epilepsy awareness among general public
3. Training of primary care physicians and postgraduate residents.

Summary of Activities in Relation to Global Campaign in 2015 and 2016

Repeat paid telecast of epilepsy documentary. Continued 'paid telecast' of the 5 min epilepsy awareness documentary, done on prominent regional satellite television channels in all four provinces in the regional languages. It was telecast twice a day every

day for three months on various regional television networks. These channels are not only watched in the country, but by communities speaking the language in the neighbouring countries, as well as in far off places like the Middle East and the UK. This activity is stressed to further enhance the ongoing epilepsy awareness amongst the masses. It has proven to be the most cost effective awareness method requiring no human resources and maximum geographical reach. Celebrating Epilepsy Day, The International Epilepsy Day was marked by actively broadcasting epilepsy awareness messages on various FM radio channels for the entire day. Awareness posters and billboards were put up on various main roads and in the city centre for the general public. March 2016: International Women's Day, 'Highlighting women with Epilepsy, A workshop on women with epilepsy (WWE)' was organized on International Women's Day. The workshop was held at Najmuddin Auditorium, Jinnah Postgraduate Medical Centre in Karachi on 8th March 2016. The International Women's Day theme for this year, "Pledge for Parity", was the central theme of this workshop, too. It was attended by approximately 80 participants, including professionals from various fields of medicine and surgery, and patients with epilepsy and their attendants. Speakers included Prof. Hasan Aziz, Prof. Naila Shahbaz and Dr. Zarine Mogal. Prof. Naila spoke on the stigma associated with WWE and pledge for parity. Dr. Zarine spoke about special issues unique to WWE and discussed the treatment and management issues exclusively encountered while treating women. Under the title "Yes we can", a few brave young WWE were invited to come on stage and share their experiences on living with epilepsy. They spoke about how they overcame their medical problem with proper treatment and support of their family, friends and doctors to succeed domestically, academically and professionally in life. This was an eye-opener and motivational for the audience.

Educational Activities

December 2016: ILAE ASEPA Epilepsy Teaching Course, a two-day Teaching Course in Epilepsy was conducted in Lahore and Karachi in the first week of December 2016. The course was organized by the Asian Epilepsy Academy (ASEPA), an educational arm of the Commission on Asian & Oceanian Affairs, International League against Epilepsy, in collaboration with the National Epilepsy Centre (NEC) and Epilepsy Association of Pakistan (EAP). ASEPA tutor speakers included Emeritus Professor Jing Jang Tsai (Taiwan), Professor Chong-Tin Tan (Malaysia), Dr. Zebunnessa Rahman (Australia), Dr. Ahmad Rithaiddin (Malaysia) and Dr. Zarine Mogal (Pakistan). Emeritus Professor Hasan Aziz (Pakistan) was the guest speaker. This two-day workshop was enthusiastically attended by senior and junior doctors from all fields of neurosciences. The workshop was a combination of didactic lectures



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and interactive case-based discussions which comprehensively covered all aspects of diagnosis, treatment and holistic management of epilepsy in adults as well as paediatric populations. Lectures and discussions were followed by Q&A sessions in which audiences, particularly junior doctors, eagerly participated and the tutor speakers gladly shared their knowledge and experiences in epilepsy. Ongoing CMEs to update the primary care physicians and postgraduate residents with regards to epilepsy.

Future Plans

Projects in development to enhance public awareness and organize training programs for primary care physicians and postgraduate students.

Officer Election Date

4th June 2016

Report by

Dr. Zarine Mogal, Dr. Hiba Mahmud

PARAGUAYAN LEAGUE AGAINST EPILEPSY

Summary of Activities in 2015/16

- Course of primary care in epilepsy. (Lat Affairs Commission, Primary Care in Epilepsy). 18-19 November 2016.
- Epilepsy Week Paraguay-Bolivia. 27 and 28 June 2016.
- APS course in epilepsy. July 1, 2016.
- Training day for the general public. July 2, 2016.
- Update on epilepsy (APS) in the interior of the country. (Cities of Paraguari, Caacupe and San Estanislao).
- Latin American Day of Epilepsy. (September 9, 2016) Talks about epilepsy for patients. (Regional Hospital of Luque). Activities: Attendance at Lipalep.

Summary of Activities in Relation to Global Campaign in 2015 and 2016

- Course of primary care in epilepsy. (Lat Affairs Commission, Primary Care in Epilepsy). Declared of national interest by the Ministry of Public Health and Social Welfare of the Republic.
- Epilepsy Week Paraguay-Bolivia. Activity organized in conjunction with the Bolivian Chapter of ILAE.
- Update in epilepsy (APS) in the interior of the country. Conducted throughout the year in different cities in the interior of the country.

- Latin American Day of Epilepsy. (September 9, 2016) Commemoration in main hospitals of Asunción.
- Educational activities
- See previous sections.

Future Plans

- Follow-up of educational activities. Epilepsy Week Paraguay. Course ALADE Paraguay 2017.
- Follow-up on the Project to Protect the Patient with Epilepsy.

Report by

Dr. Silvia Abente (General Secretary Lipalep)

POLISH SOCIETY OF EPILEPTOLOGY

Publications

Published a book (in Polish) for neurologists, GPs, psychiatrists, neuropediatricians.... "Differential diagnosis of epilepsy and other paroxysmal disorders". Contribution to PZWL, 2015. In progress is a book (in Polish) for neurologists GPs, psychiatrists, neuropediatricians "Semiology of epileptic seizures"

Meeting

In 2016, XXVII Congress on Epilepsy organized by Polish Society on Epileptology, Warsaw 05; 400 participants. In 2015: XXVI Conference on Epilepsy organized by Polish Society on Epileptology, Warsaw 05; 375 participants. The national experts on various fields of epilepsy were invited to give lectures. The topics covered were: epilepsy and pregnancy, video-egg diagnostic values in different types of epileptic syndromes and non-epileptic events. The differential diagnostic difficulties from endocrinologic and epileptologic perspective were presented. With psychologists, there was a presentation of importance of the proper communication with patients with epilepsy in the field of sexual functions. During the last years, we have introduced, especially addressed to our young participants a cycle of didactic sessions. It is extremely uplifting and indicates the need for continuous education. We have discussed the motor paroxysmal episodes in children and adults. During a satellite symposium, we talked about the important theme of personalized medicine in epilepsy. In panel discussion, we considered the need for individualized treatment in patients with epilepsy. We presented the usefulness of genetics in diagnosis of epilepsy. Discussion convened by the Polish Society of Epileptology, focused on medical and social aspects of epilepsy, namely driving license and daily problems for patients with epilepsy, their needs and limitations.



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Summary of Activities in 2015/16

Many public lectures and discussion group meetings have been organized with neurologists - public health awareness. Organization forum for key opinion leaders across medicine, government, and health systems. It was very important to discuss the use of valproate for the treatment of epilepsy in female children and adolescents, and in women of childbearing potential, in the context of new warnings of EMA. Polish Society of Epileptology with Child Neurology Society presented their opinion according using marijuana in the treatment of epilepsy, pointing to the need of reliable studies.

Summary of Activities in Relation to Global Campaign in 2015 and 2016

Patronizing and supporting the Valentine Epilepsy Days every year on 14 February. 'Notice Me' is the national campaign of different patients' associations from the whole of Poland. It was launched on 14th February 2009 in Warsaw. In 2015, PSE prepared the report of differences of daily activities between patients free of seizures and with seizures. An important part of our activities in 2015 and 2016 contacts with the Ministry of Health and National Health Fund. The main problem is the reimbursement for patients of new AEDs in epilepsy. Finally, levetiracetam is free for patients in newly diagnosed (I line) epilepsy, retigabine and lacosimide are free for patients with III line of treatment epilepsy. Preparation research paper based on survey of epileptic patients' willingness to talk about sex life. Computer-Assisted Web Interview was used to collect data. The survey was available on-line on "The same as me" website. The results give the possibility to evaluate patients' needs and expectations in communications between doctors and patients in the field of their sex life. This will allow us to prepare a strategy to communicate with patients with epilepsy with sexual problems.

Educational Activities

Regular educational courses and workshops on epilepsy in Poland. Working group on epilepsy and pregnancy, on quality of life, with the elaboration and validation of an original questionnaire for patients and caregivers. Working group on videos, with the collection of informative videos on different seizure types and elaboration of appropriate tools for the didactic presentation of the material. We introduced interactive workshops pointing to errors in communication between patient-neurologist using actors and recorded scenes. Scenario was prepared by an epileptologist and interpersonal communication coach.

Activities in Conjunction with the Local IBE Affiliate

Continue helping the activity of the organization, having an umbrella function and coordinating the local societies. Patronizing the Valentine Epilepsy Days. At the moment in Poland, there exists 14 organizations of patients (nine of them are district chapters of Polish People Suffering from Epilepsy established in 1985). Cooperation with website "The same as me" devoted to patients with epilepsy as a forum and information prepared by neurologists.

Future Plans

To continue the regular educational courses. To elaborate the new standards of the quality control to epilepsy care in Poland. To prepare in cooperation with Polish Society of Gynaecologists standards for management with women with epilepsy in reproductive age. We have prepared with Polish Neurological Society the project of national Guidelines of diagnosis of epilepsy in adult and children.

Officer Election Date

2018

Report by

Joanna Jędrzejczak

QATAR LEAGUE AGAINST EPILEPSY

Publications

An article written by Hassan Al Haile Al Hail entitled "Epidemiology and Etiology of Intractable Epilepsy in Qatar" was published in the Qatar Medical Journal Volume13/Number1 in June of 2004, pages 11-13. Epilepsy in Qatar: Causes, treatment, and outcome. – NCBI <https://www.ncbi.nlm.nih.gov/pubmed/27588359>Epilepsy Behav. 2016 Aug 30;63:98-102. doi: 10.1016/j.yebeh.2016.07.043. [Epub ahead of print]. Epilepsy in Qatar: Causes, treatment, and outcome. Haddad, Hassan Al Haile Al Hail, Boulouar Mesraoua , Gayane Melikyan

Meeting

Summary of Activities in 2015/16

Activities included:

- The Qatar Annual Neurology and Epilepsy Meeting in February 2015 and 2016.
- Celebration of Epilepsy Awareness Day on March 26, 2015 and 2016
- Sending five neurologists from Hamad Hospital to attend the 28th International Epilepsy Congress on July 2015 in Turkey.
- Sending six neurologists to attend the recently held Saudi Emirate Epilepsy Conference. ILAE April 2016



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- Sending six neurologists from Hamad Hospital to attend the AAN Congress in the USA in April 2015 and 2016

Summary of Activities in Relation to Global Campaign in 2015 and 2016

Educational Activities

Opened epilepsy monitor unit with two beds.

Head of Epilepsy unit: Dr Boulenouar Mesraoua and vice Dr H Al Hail.

Monitored more than 80 cases and planning to increase the number of beds.

- Several training workshops on electroencephalography for young neurologists were held in the Department of Neurology at Hamad General Hospital.
- We provide regular training for medical students from Weil Cornell Medical Faculty in Doha, as well as hospital staff including emergency staff on how to deal with seizure and status epilepticus management
- We participate in epilepsy cases in EEG-Videos case hospital's weekly "neurology grand rounds and epilepsy ground. Additionally, the League offers exchange programs for internationally known neurologists and epileptologists serving as visiting consultants for patient care and lecture presentations. Last year, we invited Dr. Wissner from Switzerland and Dr. E. Perucca from Italy, as well as many other neurologists from the region, to the 6th Qatar Regional Neurology Conference. In February 2014, different international and national speakers focused on epilepsy and other neurology topics at the 7th Qatar Neurology Conference. We had several topics related to epilepsy written by Boulenouar Mesraoua, Dirk Deleu, Hassan Al Hail, Gayane Melikyan and Heinz Grego Wieser, that were specifically related to different aspects of JME, diagnosis and treatment. Several educational media programs about epilepsy were made for local Qatar TV and published in local newspapers. An intranet site was established in our hospital website.

The site, <http://qatarneuroscience.webs.com>, focuses on epilepsy education. Our neurology department staff members have attended and participated in many regional, local and international epilepsy conferences over the last two years.

Activities in Conjunction with Local IBE Affiliate

The Qatar League against Epilepsy (QLAE) was established in 1995 and, since that time, is part of the Qatar Chapter of the International League against Epilepsy (ILAE) and the International Bureau

of Epilepsy. During recent years, QLAE has initiated several educational and Congress-related activities. Several local and regional (Gulf Region) neurology and epilepsy conferences also took place. An invitation will be sent to the IBE office for our annual neurology conference, so that they can share and exchange knowledge with us.

Future Plans

- There will be an upcoming 9th Annual Neurology Conference, including the Qatar Chapter of Epilepsy, and Epilepsy Awareness Day will take place in February 2017.
- We have already built up a comprehensive epilepsy center.

Current Officer roster with e-mails

Dr. Hassan Jassim Al Hail, President
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Osama El Alamy Vice Treasurer
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Officer Election Date

October 2018

Report by

Dr. Hassan Al Hail and Dr. Boulenouar Mesraoua and Dr. Tage Eldin Sokrab

ROMANIAN SOCIETY AGAINST EPILEPSY (SIRE)

Meeting

Annual National Conference of the Romanian Society Against Epilepsy

Summary of Activities in 2015/16

2015

- Course "Resistant Epilepsies" – Centrul de zi Exista Speranta (Day Care Center – There is Hope), Bucharest 20-22 Apr 2015 – Invited



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guest – Olivier Dulac (<http://www.dravet.ro/noutati-si-evenimente/evenimente-2015/profesorul-olivier-dulac-da-consultatii-la-centrul-exista-speranta>)

- Workshop: “Dravet Syndrome – Diagnosis & Treatment” – Novotel Hotel Bucharest – 13-14 March 2015 – Invited guests: Charlotte Dravet and Catherine Chiron (<http://srnp.ro/dravet-syndrome/>)
- Preconference Course - EEG - practical issues - 19 Nov.2015, Bucharest
- The XXIIIrd Annual SRIE Conference – 19-21 Nov 2015, Bucharest, 19-21 Nov 2015 (<http://ilae-romania.ro/the-xiii-srie-conference/>) – Invited guests: Meir Bialer, Walter van Emde Boas, Olivier Delalande, Olivier Dulac, Thea Gutter
- Common Patient Dravet Association – SRIE – Discussion of social issues (<http://www.dravet.ro/noutati-si-evenimente/evenimente-2015/conferinta-srie-la-care-dravet-romania-a-fost-invitata-sa-sustina-o-prezentare-despre-rolul-asociațiilor-de-pacienți>)
- Theatre Play Hurrah Nosferatu! 29 August 2015 – National Theater Bucharest (<http://www.dravet.ro/noutati-si-evenimente/evenimente-2015/piesa-de-teatru-noroc-nosferatu-despre-viata-cu-sindromul-dravet; http://netaart.tv/neta-international-theatre-festival-is-coming-to-bucharest-28-8-4-9-2015/>); CEA –ILAE members, having the Summer meeting in Bucharest at that time, and participated at this theatre play.

2016

- Public Debate – at Deputy Chamber, Parliament Palace, 28 March 2016 “Epilepsy- A public health issue” – participants: representatives from the Ministry of Health, Drug Agency Romania, Insurance House Romania, Romanian Society Against Epilepsy, patient organizations, President of Deputy Chamber, medical doctors (<http://www.politicidesanatare.ro/problemele-pacientilor-cu-epilepsie-dezbatute-de-specialisti-autoritati-si-pacienti/>) ; Guest – Athanasios Covanis, IBE
- SRIE Summer School & The 2nd East-European Epilepsy Course – 15-17 June 2016, Cheile Gradistei, Romania (<http://ilae-romania.ro/srie-summer-school-2-east-european-epilepsy-course/>) – Invited guests: Meir Bialer, Eugen Trinkka, Alla Guekht, Lorella Minotti, Nicola Specchio, Nebojsa Jovic, Carmen Barba, Dragoslav Sokic, Stanislav Groppa.
- Preconference Course: Treatment in Epilepsy - 17 Nov 2016

- The XXIVst Annual SRIE Conference – Bucharest, 17-19 Nov 2016 (<http://ilae-romania.ro/the-xxivth-srie-conference/>) – Invited guests: Petia Dimova, Stanislav Groppa, Hans Holthausen, Joanna Jedrzejczak, Reetta Kälviäinen, Lorella Minotti.
- Working group for finding solutions for patient and access to efficient therapies – 17 November 2016 – Hotel Capitol, Bucharest. Participants: representatives from the Ministry of Health, Drug Agency Romania, Insurance House Romania, Romanian Society Against Epilepsy, Patients organizations, medical doctors.

Summary of Activities in Relation to Global Campaign in 2015 and 2016

2015

- Theatre Play Hurrah Nosferatu! 29 August 2015 – National Theater Bucharest (<http://www.dravet.ro/noutati-si-evenimente/evenimente-2015/piesa-de-teatru-noroc-nosferatu-despre-viata-cu-sindromul-dravet; http://netaart.tv/neta-international-theatre-festival-is-coming-to-bucharest-28-8-4-9-2015/>); CEA –ILAE members, having the Summer meeting in Bucharest at that time, and participated at this theatre play.

2016

- Public Debate – at Deputy Chamber, Parliament Palace, 28 March 2016 “Epilepsy- A public health issue” – participants: representatives from the Ministry of Health, Drug Agency Romania, Insurance House Romania, Romanian Society Against Epilepsy, Patient organizations, President of Deputy Chamber, medical doctors (<http://www.politicidesanatare.ro/problemele-pacientilor-cu-epilepsie-dezbatute-de-specialisti-autoritati-si-pacienti/>); Guest – Athanasios Covanis, IBE
- Working group for finding solutions for patients access to efficient therapies – 17 November 2016 – Hotel Capitol, Bucharest. Participants: representatives from the Ministry of Health, Drug Agency Romania, Insurance House Romania, Romanian Society Against Epilepsy, patient organizations, medical doctors.

Educational Activities

2015

- Course “Resistant Epilepsies” – Centrul de zi Exista Speranta (Day Care Center – There is Hope), Bucharest 20-22 Apr 2015 – Invited guest – Olivier Dulac (<http://www.dravet.ro/noutati-si-evenimente/evenimente-2015/profesorul-olivier-dulac-da-consultatii-la-centrul-exista-speranta>)



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- Workshop: “Dravet Syndrome – Diagnosis & Treatment” – NovotelHotel Bucharest – 13-14 March 2015 – Invited guests: Charlotte Dravet and Catherine Chiron (<http://srnp.ro/dravet-syndrome/>)
- Preconference Course - EEG - practical issues - 19 Nov.2015, Bucharest; teachers: Walter van Emde Boas, Thea Gutter

2016

- SRIE Summer School & the 2nd East-European Epilepsy Course – 15-17 June 2016, Cheile Gradistei, Romania (<http://ilae-romania.ro/srie-summer-school-2-east-european-epilepsy-course/>) – Invited guests: Meir Bialer, Eugen Trinko, Alla Guekht, Lorella Minotti, Nicola Specchio, Nebojsa Jovic, Carmen Barba, Dragoslav Sokic, Stanislav Groppa.
- Preconference Course: Treatment in Epilepsy, woman with epilepsy - 17 Nov 2016, Bucharest

Future Plans

- 26 March 2017 - Argue for the purple illumination of public buildings in Bucharest
- 26 March 2017 - Action with Dravet and other rare epilepsies association - Raising awareness on epilepsy
- 26 March 2017 - commom action with Cyclists association - Bucharest March on bicycle for epilepsy day
- Finalise syllabus for EEG technicians and obtain recognition from the Ministry of Health, Romania
- SRIE Summer school - Investigations in epilepsy
- SRIE-ASNER (Neurophysiology association)-SNR (Neurology Association) – May 2017 – EEG course
- The XXVth Annual SRIE Conference – Nov 2017, Bucharest, 19-21 Nov 2015
- Renew and reprint – informative booklet for patients with epilepsy
- Extend cooperation with neighboring countries from Eastern and Central Europe for exchange and development

Officer Election Date

Nov 2015-Nov 2019

Report by

Dana Craiu, President of the Romanian Chapter

SAUDI CHAPTER EPILEPSY

Publications

Multiple

Meeting

Quarterly

Summary of Activities in 2015/16

- I. GULF LEAGUE AGAINST EPILEPSY SOCIETY
The most important achievement the during this period was the formation of GCC Epilepsy Society and all GCC members agreed that the President of SES will be the GCC Epilepsy Society President, too. New constitution and bylaws have been implemented Gulf League against Epilepsy.
- II. EPILEPSY AND DRIVING After a long discussion Mr. Ali Zahrani (Transport department) had agreed to make a policy about epilepsy and driving. Hopefully it will be implemented soon in the Kingdom.
- III. SES WEBSITE SES website was launched in September, 2014. Previous website linked to the new one.
- IV. SES MAGAZINE Established magazine under the name of epilepsy. The title of the magazine is “Epilepsy Waves”. It is the main magazine for the Saudi Epilepsy Society to publish scientific articles, and news related to national and international level. It will be directed by physicians and it’s linked to the SES website.
- V. SES BOOKLET The second Arabic patient support publication, which was edited by all members, was published.
- VI. SES ACCOUNT Account opened in Saudi Hollandi bank for the SES membership.
- VII. NEW BUDGET The main source of budget income is through meetings, courses and educational courses, and conferences related to SES in addition to charity.
- VIII. NEWLY ADDED COMMITTEES Two new committees added to the previous seven existing committees:
 - i. Neuroradiology Committee
 - ii. Epilepsy Guidelines and Regulation Committee
- IX. Research study related to epidemiology of epilepsy in Saudi Arabia has been done.
- X. REVISION OF SES BYLAWS AND CONSTITUTION Third revision of SES bylaws and constitution has been done.



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XI EDUCATIONAL ACTIVITIES

- i. 21st SAUDI NEUROSCIENCE MEETING
Conducted in Riyadh on November 23-25, 2013 in collaboration with SES
- ii. THE 3rd ANNUAL UAE EPILEPSY CONGRESS & 1st JOINT EMIRATI SAUDI EPILEPSY CONGRESS Held in Dubai on April, 2014
- iii. 4th ANNUAL CONFERENCE Conducted on November 26-27, 2014 @ Ritz Carlton Hotel, Riyadh
- iv. SAUDI INTERNATIONAL PEDIATRIC NEUROLOGY CONFERENCE Held in KFMC, Riyadh on November 9-10, 2014
- v. One-day course conducted about neuroradiology on 25 September, 2014 @ KFSH-Dammam
- vi. Some SES members are being recognized internationally and were invited to International Epilepsy Congress. eg; members speak in 31st IEC (International Epilepsy Congress) in Istanbul on 6-10, September, 2015 and others participated in Scientific Committee in 3rd East Medicine Epilepsy Congress in Jordan, 19-21 March, 2015
- vii. Workshop conducted regarding KGD on 26 March, 2015 @ KFSH, Dammam
- viii. Pediatric and adult epilepsy courses conducted in Hail on 28 May, 2015
- ix. One-day course regarding updates of diagnosis and treatment in epilepsy & public awareness conducted on 13th August @ Amal Complex for Mental Health, Dammam
- x. 5th SES & 1st GCC EPILEPSY CONFERENCE Held on 7-9 November, 2015 @ Le-Meridien, Al Khobar
- xi. SANS & CEMA SES actively participated in 10th SANS conference on 1-3 March, 2016 @ Ritz Carlton, Riyadh and trophy was presented to the society. Also SES participated in the conference of CEMA on 4-5 March, 2016 in Dubai with an excellent presentation and attendance
- xii. EPILEPSY AWARENESS DAY-2015 The first time in KSA, World Epilepsy Day conducted in six cities with Novartis SES playing an important role in the resolution of WHA (World Health Assembly) in Feb. 2015 which is an important landmark to improve services and care for people with epilepsy. Epilepsy & driving guidelines. Research related to epilepsy: e.g. epidemiology

Activities in conjunction with local IBE affiliate

Multiple awareness days to communities.

Future Plans

SES MAGAZINE, "Epilepsy Waves": - To publish scientific articles, and news related to national and international level. It will be directed by physicians and it's linked to the SES website. To find residence for SES. Fund raising (significant increase over the last three yrs). Promote awareness and education epilepsy to reach remote areas in Saudi Arabia. Combine the effort of all members of SES members by forming scientific committees, and outreach members. To continue the communication with CEMA, IBE & ILAE. Shall serve all health professionals as the premier national resource for current and emerging knowledge on epilepsy prevention, awareness, diagnosis, treatment and research. Development guidelines related to epilepsy in Saudi Arabia.

Officer Election Date

03/19

Report by

Raidah Albaradie

SERBIA AND MONTENEGRO: UNION OF SERBIAN AND MONTENEGRIN LEAGUES AGAINST EPILEPSY

Publications

Series of proceedings: "Appropriate time for decisions in the clinical management of patients with epilepsy?" (17th Epilepsy School, 2015), "Seizure etiology – Key for the therapeutic decision" (18th Epilepsy School, 2016).

Summary of Activities in 2015/16

10th Congress of Serbian Neurologists with international participation (Novi Sad, October 22-24, 2015) included teaching course ("Management of patients with epilepsy during its clinical course") and a number of sessions on epilepsies. Educational cycle of Epilepsy School courses: - 17th Epilepsy School, November 2015 - 18th Epilepsy School, November 2016 - Participation with the Project of EURAP. Collaboration with a number of other national ILAE Chapters, especially with regional Leagues of Bulgaria, FYRM and Croatia. Our National Chapter strongly promoted the regional collaboration and initiated some professional and scientific projects.



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Summary of Activities in Relation to Global Campaign in 2015 and 2016

Educational and public-awareness activities (press and visual media) Lectures on: 1) Stigmatization and social isolation of subjects with epilepsy 2) Difficulties in professional occupation and driving license procedures 3) Quality of life in patients with severe, disabling epilepsy and impact of epilepsy surgery on daily life capacities.

Educational Activities

- 17th Epilepsy School, November 27-29, 2015, Kotor, Montenegro.
- Course on Epilepsy in Neurocutaneous Disorders, November 14, 2015, Belgrade (joint event of the national Chapter and Serbian TSC association)
- CME course: Diagnosis and Therapy of Epilepsy through the Ages, in co-organization with Medical School of Nish
- 18th Epilepsy School, November 11-13, 2016, Andrevlje, Banostor, Serbia.

Activities in Conjunction with Local IBE Affiliate

No activities of local IBE were recognized for years No activities in conjunction with local IBE. Chapter does not find that local IBE still exists.

Future Plans

1. 19th Epilepsy School, Soko Banja, Serbia, September, 2017.
2. 20th Epilepsy School, Andrevlje, Banostor, Serbia, November, 2018.
3. 5th EEG Workshop, Andrevlje, Banostor, Serbia, November, 2018.
4. Workshop on mTOR inhibitors for epilepsy in Tuberos Sclerosis Complex, April 2017.
5. Workshop on Driver license issues and epilepsy May, 2018
6. 11th Serbian Neurology Congress, Belgrade, November 2017.
7. 4th Epilepsy Congress of Serbia and Montenegro – 2017

Report by

Prof. Dr. Nebojsa J.Jovic, Chapter President

SLOVAK LEAGUE AGAINST EPILEPSY

Publications

Four articles in Slovak language, SLPE guidelines on epileptology

Meeting

Two meetings

Summary of Activities in 2015/16

Participation in Epilepsy Congress, Prague 2016

Child epilepsy congress

Active participation in 69th Annual meeting of AES.

December 4 – 8, 2015 Philadelphia PA. USA

Postgraduate courses on child epilepsy

Summary of Activities in Relation to Global Campaign in 2015 and 2016

Article in the magazine about epilepsy

Educational Activities

Postgraduate courses on EEG under Slovak Medical University

Activities in Conjunction with Local IBE Affiliate

Cooperation with local IBE branch (Aura)

Future Plans

Cooperation with health and medical board of the regular authorities

Control issues of epilepsy and EEG at DRG applications

Officer Election Date

2020

Report by

Vladimir Donath

SOUTH AFRICAN CHAPTER OF THE ILAE

Publications

- Epileptic spasm 175 years on (review article) Wilmhurst et al 2016 Dec
- Treatment of infants with epilepsy: Epilepsia 2015 Wilmhurst et al
- Medical management of children with epilepsy (Review) Minerva Pediatric 2015 Ackerman S, Wilmhurst

Summary of Activities in 2015/16

- A web based interactive teaching program on EEGs is almost ready to be launched to serve various countries in Sub Saharan countries. Funding was secured from the World Federation of Neurology. This will be facilitated by experts from various provinces in the country



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- Annual symposium for general practitioners held in Pretoria: teaching includes topics like epilepsy
- Various TV interviews given on the topic of epilepsy
- A presentation on epilepsy given to “Doctors Without Borders” in Johannesburg – to forge a cooperation
- The African Pediatric fellowship program based in Red Cross continues to train African child health professionals from various countries in the Sub Saharan region (between 2008 – 2015, 73 doctors trained/ in training).

Summary of Activities in Relation to Global Campaign in 2015 and 2016

EEG web-based teaching program - subsaharan Africa Red Cross based training program with collaboration with various countries in the subsaharan region

Educational Activities

- Web based EEG program to be launched
- Continued education (Symposia for general practitioners)
- NASA (Neurological Association of South Africa): Annual event for adult Neurologists
- Rural teaching symposia facilitated by the Colleges of Medicine of South Africa

Activities in Conjunction with Local IBE Affiliate

Epilepsy South Africa continues to be active in supporting of programs related to epilepsy in various parts of the country.

Future Plans

To expand teaching programs and awareness campaigns in the more remote parts of the country.

Officer Election Date

The present President and members were elected in 2013.

Report by

DS Magazito

SWEDISH EPILEPSY SOCIETY

Publications

Please visit our Website for educational programs and guidelines. www.svenskaepsallskapet.se

Meeting

The Society’s Annual Meeting took place November 6-7, 2016

Summary of Activities in 2015/16

A workshop was held in October 2015 titled “Update on Genetics in Epilepsy and Epileptic Encephalopathy”. The Annual Meeting 2015 focused on “Biomarkers in Epilepsy”. In spring 2016, a workshop was held exploring the question “Gene therapy for epileptogenesis: how close are we to the clinic?” A two day course was given in October 2016 on “Classification of Cortical dysplasia in epilepsy”. The Annual Meeting 2016 dealt with “Neuromodulation in Epilepsy: Vagus Nerve Stimulation and Deep Brain Stimulation”

Summary of Activities in Relation to Global Campaign in 2015 and 2016

Members of the Swedish Epilepsy Society have, during 2015 and 2016, completed an update of a 20-year-old book on basic epileptology. It is called “Epilepsiboken” (The Epilepsy Book) and the press release took place on International Epilepsy Day 2016 in the Houses of Parliament in Stockholm. The book is covering a broad spectrum of what you need to know about epilepsy, being a patient, relative, young student or hospital staff. The information is readily available, presented in an easily understandable way even if it covers complicated issues, and the book is a welcome tool to increase the knowledge of epilepsy in Sweden. The book release is a result of cooperation between the authors and the local IBE affiliates.

Educational Activities

A national epilepsy register for children was completed and implementation started during 2016. The epilepsy register for adults started in 2014 and the implementation for expanded use among colleagues over the country is ongoing, but slow. We offer an annual educational course for neurology residency training as well as updates on epileptology for colleagues in neurology in collaboration with the Swedish Neurological Society, since 2015. We offered educational courses for physicians and nurses in epileptology. During 2016, the process of conducting national guidelines for epilepsy has started at the request of the Swedish Government. The guidelines are planned to be completed during 2019 and apply to both adults and children. The Society established clinical advice for professionals regarding epilepsy care to adults in 2014 and similar documents have been completed for children with epilepsy, during 2016. The Swedish Epilepsy Society has awarded scholarships to several members to improve and facilitate the advancement of epileptology within the Swedish medical community.

Activities in Conjunction with Local IBE Affiliate

The Epilepsy Book is a result of cooperation between the Swedish Epilepsy Society and the local IBE affiliates,



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as above. Representatives from the local IBE are taking part in the development of the National Guidelines for epilepsy as well as through continuous work to spread the use of the Epilepsy register. Media contacts and press releases. Local joint activities in different cities on International Epilepsy day.

Future Plans

We will continue to offer annual courses and workshops to increase knowledge about epilepsy, as well as work for accessible updates on epileptology. In addition, we will promote research and development of epileptology in Sweden; the current work on national guidelines for equal and adequate care of patients with epilepsy is our priority. Further development of the Epilepsy register is another important field.

Officer Election Date

November 17, 2016

Report by

Ulla Lindbom, President

SWISS LEAGUE AGAINST EPILEPSY

Publications

Regular Publications

- Journal "Epileptologie" (Epileptology), published four times a year, 50 - 70 pages each, with information about new developments in epilepsy research and treatment (for professionals, 1,100 copies). Articles in English, German, or French with summaries in all three languages. Topics 2015: History of EEG and epileptology in Switzerland / Pharmacology / Genetics / Ethics. Topics 2016: Epilepsy, cognition and mental state / Epilepsy in the first year of life / Non-epileptic EEG diagnostics / First seizure: What's next?
- Newsletter "Epilepsie-News", published three times a year, four pages each, with information about our activities and about epilepsy (for donors and members, about 22,000 copies in German, about 8,000 copies in French).
- Annual booklet on events in German and French
- Annual report (German, French)
- Website www.epi.ch (German, French, Italian with some English information)
- Monthly e-newsletter (about 10,000 German-speaking and 3,600 French-speaking recipients)
- E-Newsletter for doctors (news in 2016; about 2-3 times per year)

Meeting

2015

- 9th Joint Meeting of the German, Austrian and Swiss Chapters of the International League Against Epilepsy (ILAE) in Dresden, Germany, April 22-25, 2015.

2016

- Annual Congress of the Swiss League against Epilepsy with the Swiss Society for Sleep Research, Sleep Medicine and Chronobiology (SSSSC), in Basel, April 28-29, 2016.

Participation in different scientific events.

Summary of Activities in 2015/16

- Campaign "Youth and Epilepsy" with a special website for young people and two short films; promotion via social media (Facebook, YouTube) and the press
- Continuing presence on Facebook
- Updated information leaflets "Driver's license with epilepsy" (German, French, Italian) and "Seizure first aid" (German)
- New information leaflet "Non-epileptic seizures" (German, French)
- New brochure presenting the League in general (English, German, French, Italian)
- Record of seizures with new layout as PDF (can be filled in electronically)
- SOS card with new layout (German and French)
- Three annual events with about three lectures each, for professionals and non-professionals, in different cities
- Additional event at Brainweek Berne
- Annual Research Recognition Award (CHF 25,000) for the most promising research study in Switzerland in the field of epileptology
- Biannual Hauptmann Award in 2015 (Euro 10,000) in cooperation with the German and Austrian Chapters
- Prize for Best Dissertation in 2016 (1,000 CHF every three years)
- Campaign "Epilepsy in the elderly": Continuing education for (geriatric) nurses and PR in German and French
- Media activities
- Answers to medical questions, about 130 questions a year
- Three medical articles on doctors' network "coliquio.ch"



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Summary of Activities in Relation to Global Campaign in 2015 and 2016

Annual events for the German-speaking "Epilepsy Day" (October 5):

- 2015: Public event with lectures and music
- 2016: Two public readings with Sarah Elise Bischof, young author of "Panther days – My life with epilepsy"

Educational Activities

- Annual "Patients' Day" on life with epilepsy
- Annual training event for sponsors (pharmaceutical industry)
- Seizure first aid classes for several large companies
- Training events for nurses concerning "Epilepsy in the elderly"

Activities in conjunction with local IBE affiliate

Several common events and publications, such as epilepsy emergency card.

New written agreement on cooperation.

Future Plans

- Regular activities and publications as before
- Support for a documentary film about a family's decision to have their child with epilepsy operated
- Get selected publications translated into minority languages in Switzerland, i.e. Albanian, Portuguese, Croatian/Serbian
- New fundraising strategy
- New website

Current Officer Roster with e-mails

Elections April 2016:

New President, Stephan Rüegg

New Vice President, Andrea Rossetti

New Treasurer, Elmar Zwahlen

New Board members, Pamela Agazzi and Kaspar Schindler;

Past-President, Günter Krämer.

Re-elected: Alexandre Datta, Thomas Grunwald, Anna Maria Hew-Winzeler, Malin Maeder, Klaus Meyer, Markus Schmutz, Margitta Seeck, Urs Sennhauser.

Officer Election Date

Spring 2018

Report by

Julia Franke

TAIWAN EPILEPSY SOCIETY

Publications

Taiwan EEG guideline, Taiwan epilepsy guideline

Meeting

Annual Meeting

Summary of Activities in 2015/16

Annual meeting of Taiwan Epilepsy Society: Annual meeting of Taiwan Epilepsy Society was held on March 26-27, 2016, at Sheraton Grande Taipei Hotel. We defined the meeting as "The Way to Precision Medicine for Epilepsy." There was a pre-congress meeting "talking with masters" in the afternoon of March 26. We have six young adult neurologists and pediatric neurologists in the session to present interesting cases for interactive discussion, with our honorable guest, Professor Jean Gotman (Canada), Professor Jeffrey L Noebels (USA), and many outstanding masters from Taiwan.

Summary of Activities in Relation to Global Campaign in 2015 and 2016

Epilepsy Diary Application (App): There was another exciting activity - press conference to announce the launch of Epilepsy Diary App, sponsored by GlaxoSmithKline (GSK) Pharmaceuticals with our Society, held on Oct.04, in Taipei. The App showed an easier and convenient way to record daily life of people with epilepsy; including seizures, medications and eventreminders. The more precise the record is, more effective management we have; the great success of the press conference will promote concept of "precise and effective communication between patients and healthcare staff."

Educational Activities

1. Basic EEG education course-January 2016. Our Society conducts the interactive EEG education course at least once every year. Depending on the audience; we will adjust the degree of difficulty of the course. In 2013, conducted nine times with different levels, three for basic level, three for intermediate level, and three for advanced level.
2. Course of "Introduction and Managing Patients with Epilepsy" and "Introduction of Epilepsy" "Introduction and Managing Patients with Epilepsy" was conducted two times in 2016, in order to provide comprehensive epilepsy education to nursing professionals. "Introduction of Epilepsy" had been conducted three times this year. The course aimed to raise awareness, communication and education on the theme of epilepsy for school staff and nurses working in the schools. There were more than 1,000 teachers or school nurses in the courses.



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3. Young-Star Epilepsy Training Program-Nov 19, 2016; "Young-Star Epilepsy Training Program" was held once a year. This program was prepared for young investigators in neurology/neurosurgery/pediatric neurology, especially for those who just passed the Neurology Board Examination. It included three interactive workshops: Video-EEG, neuroimaging, and antiepileptic medications treatment; every participant must join all three workshops which performance will be rated as five degrees by tutors of every workshop.

Future Plans

Revision of EEG guideline and epilepsy guideline of Taiwan

Officer Election Date

March 19, 2017

Report by

Secretary General Chien Chen, M.D.

THAILAND: EPILEPSY SOCIETY OF THAILAND (EST)

Publications

1. Epilepsy Digest: Three issues/year
2. Clinical Practices Guideline for Epilepsy 2015, 4th Edition

Meeting

1. 2015: Annual Scientific Meeting: Management of difficult-to-treat epilepsy, July 22nd-24th, 2015
2. 2016: Annual Scientific Meeting: Epilepsy in everyday life, July 28th – 29th, 2016

Summary of Activities in 2015/16

2015 we and the 9th Executive Board have commenced administrative roles for a two-year term from July 2015.

- Annual scientific meeting was held in Bangkok in July 2015 and July 2016. International guest speakers were Prof Eugen Trinkka (Austria), Prof Byung In Lee (Korea), and Dr Tim Wehner (England) in 2015, and were Prof William E Rosenfeld (USA) and Prof Emilio Perucca (Italy) in 2016.
- Paperless handout has been integrated into every academic meeting since July 2015.
- Official education bulletin, called "Epilepsy Digest," has been disseminated to the members and non-members free-of-charge electronically since July 2015. It could be accessed without any fee via EST's official website www.thaiepilepsysociety.com.

- A two-day epilepsy course for in-training neurology physicians (paediatric neurology and neurology) was carried out in August 2015 and 2016. These are free-of-charge educational courses for senior neurology residents and paediatric neurology fellows.
- Celebration of the 20th anniversary of the Thai Epilepsy Society (May 23rd, 2016)
- Multicenter collaboration to conduct nationwide research on neurologists' and paediatric neurologists' perspectives on epilepsy surgery has been initiated since July 2015 and is in process at the time of this report.

Summary of Activities in Relation to Global Campaign in 2015 and 2016

The Epilepsy Association of Thailand (EAT) conducts activities for patients and caregivers regarding epilepsy care through media such as Facebook, YouTube, broadcast communication, news and seminars.

Educational Activities

- Annual Scientific Meeting: 19th Meeting: July 22nd- 24th, 2015: 20th Meeting: July 28th-29th, 2016
- Epilepsy course for in-training residents and fellows: 6th August 22nd- 23rd, 2015: 7th August 20th- 21st, 2016
- Basic EEG Workshop: 27 July 2016
- Epilepsy conference four times/year
- Epilepsy conferences with invited international guest speaker: March 10th, 2016: Prof. A Simon Harvey (Australia): November 4th, 2016: Prof. Dorothee Kasteleijn-Nolst Trenite (Netherlands)
- Ten one-day free-of-charge educational courses on epilepsy for general practitioners in various provinces in Thailand were conducted. This activity is a team-up activity with private partners and Neurology Association of Thailand

Activities in Conjunction with Local IBE Affiliate

- Public education in the recognition and treatment of epilepsy, Siam Paragon, Bangkok between November 18th -19th, 2015
- Epilepsy camp for northern epileptic patients in Chiang Mai on March 22nd, 2015
- Campaign for public education and awareness of epilepsy in university hospitals and major government hospitals in Bangkok and in many provinces of Thailand: International Epilepsy Day February 8th, 2016: Purple Day March 26th, 2016
- School activities for Purple Day: Epilepsy knowledge in school-aged children by team of Chulalongkorn Comprehensive Epilepsy Center: six times/year



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Future Plans

- To persuade Thai government to integrate epilepsy into government-support service plan
- To create and share resources for epilepsy care, especially for epilepsy surgery
- To expand the knowledge and awareness of epilepsy to the public
- To be the local host of the 33rd International Epilepsy Congress in Bangkok, Thailand in 2019

Officer Election Date

June 2017

Report by

Kamornwan Katanyuwong, M.D.

TURKISH EPILEPSY SOCIETY

Publications

Journal of Turkish Chapter of International League Against Epilepsy (in Turkish)

Meeting

3. Epilepsy symposium, 4-6 June, 2015 10. National Epilepsy Congress of Turkish chapter of ILAE, 12-15 May, 2016

Summary of Activities in 2015/16

Epilepsy meeting, monthly, 2015-2016
Semiology/ Clinical finding of Epilepsy, Workshop, 7-8 March, 2015
Status Epilepticus, Workshop, 4-8 April, 2015
3. Epilepsy Symposium, 4-6 June, 2015 EEG course (Pattern), 03 October, 17 October, 24 October, 7 November, 12 December 2015
EEG meeting, 8-9 December, 2015
Epivizyon, advanced epilepsy course, 14-15 December, 2015
Semiology, 2-3 April, 2016
Status Epilepticus, Workshop, 8 April, 2016
10. Epilepsy Congress, 12-15 May, 2016
Sivas Epilepsy Symposium II, 21 May, 2016
Episkop, case discussions, 8 October, 2016
Current treatment in Epilepsy, 21 October, 2016
Epivizyon, advanced epilepsy course, 12-13 November, 2016

Summary of Activities in Relation to Global Campaign in 2015 and 2016

Painting contest with epilepsy among children and adolescents. Photograph contest with epilepsy patients.

Educational Activities

EEG course, in four different cities.

Epilepsy course, National Neurology Congress, 2016
Bursaries to young neurologists for local and international congress

Activities in Conjunction with Local IBE Affiliate

Financial support for medical and social consultancy

Future Plans

4. Epilepsy congress, 3-5 May, 2017
11. National Epilepsy Congress of Turkish chapter of ILAE, 09-12 May, 2018
Educational activities, EEG, epilepsy course

Officer Election Date

May 2018

Report by

Kezban Aslan

BRITISH CHAPTER OF THE ILAE (UK)

Summary of Activities in 2015/16

2015 Annual Scientific Meeting - London 2016 Annual Scientific Meeting joint with Irish Chapter - Dublin
2015 Specialist Registrars weekend, Oxford 2016 Junior Doctors Concise Epilepsy Course

Summary of Activities in Relation to Global Campaign in 2015 and 2016

We have monies set aside for bursaries for those members wishing to go and teach in the area of epilepsy in developing countries. We held a session at our joint British/Irish Dublin meeting on epilepsy in developing countries.

Educational Activities

Guideline groups working on guidelines for the following: Epilepsy and Emergency Care Learning Disability and Epilepsy Video Telemetry

Activities in Conjunction with Local IBE Affiliate

We are planning to set up a small working party group for members of our chapter who are interested in epilepsy in the developing world.

Future Plans

2017 - Annual Scientific Meeting, Leeds 2017 Specialist registrars weekend, Oxford. Joint meeting



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with Society of Neuroanaesthetists of UK and Ireland late 2017/early 2018 2017 - Junior Doctors Concise Epilepsy Course

Officer Election Date
April 2016

Report by
Juliet Solomon

URUGUAYAN LEAGUE AGAINST EPILEPSY

Publications

Revista Uruguaya de Epilepsia 2015;24(1) Revista Uruguaya de Epilepsia 2016;25(1)

Meeting

Annual Meeting 2015 – Held in Montevideo, August 28th, 2015, it was organized as a training session on epilepsy for nursing professionals. Dr. Loreto Ríos and Lic Francisca Serry from Chile were our guest speakers. 44 participants from all over our country stated that the activity significantly improved their knowledge on the topic, and they expected an impact on their practice. Annual Meeting 2016 – Held in Montevideo, September 30th, 2016. In this opportunity, it was a conference and workshop on Video-EEG and MRI in epilepsy. Prof. Elza Márcia Yacubian was the invited speaker.

Summary of Activities in 2015/16

Edition of Revista Uruguaya de Epilepsia (RUE). Annual Meetings. Activities devoted to general public. New printed material (rollups, brochures, bookmarks). Self-aid groups. Support for educational activities (with Neurological Institute, Montevideo, and with the Education Commission, ILAE). Support to the National Epilepsy Surgery Program.

Summary of Activities in Relation to Global Campaign in 2015 and 2016

Mostly in the context of the Action Plan for the Americas and its strategic areas 1 and 2, we highlighted the different educational activities in which LUCE is participating (primary care physicians, nurses) as well as the continuous support to the Epilepsy Surgery Program, mainly facilitating international support (academic and equipment donations) and in the negotiations with the authorities for a permanent Estatal financial support that could allow long term sustainability. In 2016, we started a new line to approaching the community, launching an awareness campaign (“Epilepsia: creando conciencia”) with new

printed material and open activities, centered on the rights of people with epilepsy (strategic area 3).

Educational Activities

- Training workshop for primary care physicians. Joint educational activity with the Neurological Institute. Held in the city of Rocha (2015) and Florida (2016).
- Local contribution to logistics of the online course on epilepsy for primary care physicians in Latin America, organized by the Education Commission, ILAE.

Activities in Conjunction with Local IBE Affiliate

Regular activities: Independent self-aid groups for patients and relatives, both under the coordination of psychologists (Ana Bogacz, Mariela Morales). Specific activities, 2016 (complete reports in RUE 2016 - Spanish-): Participation in the “Día del Patrimonio” (held every October in Uruguay.) “Public Education”, with conferences in Museums (Figari and Gurvich museums) and talks in different open settings. Open activity for children and adults, held in Seregni Square, Montevideo, November 5th, 2016.

Future Plans

To continue and deepen the educational efforts devoted to non-medical specific populations (currently we are working to include some basic training on epilepsy in the academic curriculum of police officers). To improve and update the public awareness campaign, trying new strategies of communication with the general public.

Officer Election Date

Last election: Sept. 8th, 2012. (next election to be held mid-2017, date TBD)

Report by
Patricia Braga, President

VENEZUELAN LEAGUE AGAINST EPILEPSY

- 1) The activities carried out during the year 2015-2016 were aimed at solving the serious crisis caused by the absence of antiepileptic drugs in the country that brought the loss of many status and cases of pregnant mothers with stillbirth. We held meetings with the Ministry of Health so that they could grant the donations we requested from LIVECE and from the interior of the country.
- 2) We took a video filmed by our Past President Dr. Emilio Perucca in a call to all the organisms of



CHAPTER REPORTS

the State, giving guidance on how dangerous it is for an epileptic not to have their treatment which, in many cases, should be used for life under the risk of death because they cannot have an adequate control of their crises.

- 3) Educational programs and interviews were conducted by journalists who are knowledgeable about the subject both on the radio and on television, where many of the medical specialists also publish articles on the subject of epilepsy and the current situation due to the absence of drugs in the country.
- 4) Open conferences were held for general practitioners, nurses, and health personnel to request immediate care support for the convulsing patient.
- 5) The voluntary withdrawal of the pharmaceutical industry from the country ended up aggravating the absence of drugs. The government brings AED intermittently and in a small amount, mainly phenobarbital and valproic acid, which leads the patient taking what he finds with fatal consequences of repeated seizures, convulsive status and death.
- 6) The circumstances are so serious that in many health centers and/or public hospitals the intravenous drug "Epamin" is not available for (Diphenylhydantoin).
Many controlled epileptic patients, with more than 15 years free of crisis, have had to resort to relatives or friends to obtain their medicines at very high costs in foreign exchange.
- 7) The Venezuelan League Against Epilepsy continues to fight for all those people who require specialized consultation and maintain daily the Service of Care for children and adults, as well as the realization of electroencephalograms and the Psychological Counseling Service.
- 8) LIVECE has delivered some donations of medicines that have only served to very poorly alleviate so many patients in need.
- 9) A national consensus was made to insert two articles into the Epileptic Protection Law introduced in 2010. We have also requested a meeting with members of the new National Assembly in search for the approval of this Law.

Report by

Dra Beatriz Gonzalez Del Castillo, Past-President

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, May 2015, September 2016, March 2017

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. Article 8.3.7 of the Constitution is interpreted to mean that the Elections Commission shall be chaired by the Immediate Past President of the League. The remainder of the Commission will include the immediate Past Chair and one representative appointed by the President from each of the League's geographical regions.
2. For each phase of the election, the Elections Committee shall ascertain if candidates are available and willing to serve. Candidates will provide the Elections Committee with appropriate background information on their candidacy. This information will be sent to each Chapter and publicized in the ILAE Website. Each candidate running for election must have the support of his or her respective chapter, but not necessarily nomination (when applicable) by his or her respective chapter.
3. 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 votesChapters that do not collect dues shall have one vote.
4. 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, including any run-off election.
5. For the election of the President, the Elections Committee shall submit to the Chapters a list of persons fulfilling the requirements of the Constitution (Article VIII), who are available and willing to serve. Each candidate running for election must have the support of his or her respective chapter. 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. If this is not the case, a runoff shall be held between the two candidates who received the highest number of weighted votes. The candidate in the runoff 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.
6. Following completion of the Presidential Election, for the election of the three remaining positions of the Management Committee, the Elections Committee 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.
7. 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).
8. The Elections Committee 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 Committee shall ascertain that these candidates are available and willing to serve. Each candidate must have the support of his or her respective chapter. Individuals elected to the Management Committee must be prepared to participate on short notice in frequent discussions and activities related to day-to-day business of the League, and to provide a rapid response. Also, they must be ready to take on substantial work related to specific roles within the management committee. The above are in addition to regular meetings (by telephone or in person) which may occur every few weeks.
9. The Elections Committee 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.

10. 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.

11. Following the completion of the elections of the members of the Management Committee, the Elections Committee will proceed with the elections for membership in each of the regional commissions as follows:

A. There should be eight voting members in each regional commission. These consist of five elected members (including the chair), the immediate past-chair (if not exceeding his or her 16 year limit of voting term), plus two members appointed by the ILAE President (in consultation with the newly elected chair). For regions with more than 35 chapters, an adjustment can be made with the addition of one more elected member, making a total of nine voting members. Each voting (elected or appointed) member, including the Chairperson, must be a primary member of a different chapter (not applicable to the immediate past-chair, or to non-voting/ex-officio members). In regions where an Education Academy exists or is developed, the regional commission appoints the Director of the Academy as a non-voting member.

B. Members hold office for a period of 4 years.

C. The Chair is elected first, followed by voting for the four (or five) elected members. Voting for the Chair and then other elected members is non-weighted (with each chapter casting one vote for the chair, and voting for each of the 4 [or 5] other elected members). To be eligible for election to Chair, an individual needs to have served on the regional commission as a voting (elected or appointed) or non-voting member for at least one term (4 years), but no more than two voting terms (8 years). Past Regional Chairs (appointed or elected) are not eligible for election to a second term. The election committee on this basis will provide a list of all eligible candidates. Individuals on this list then need to agree to stand with the understanding that the Chair of the Regional Commission if elected, he/she will be a member of the Executive Committee and as such will be expected to provide thoughtful and prompt input on a large number of aspects related to the activities of the League. In addition, they will be asked to lead specific initiatives, to liaise with other groups, and to participate in annual budget reviews, which requires a substantial amount of work, in

addition to active participation in regular Committee meetings by telephone or in person. Each candidate must have the support of his or her respective chapter. Chapters will then vote for a single candidate from this list in order to elect the Chair by email, or fax. Each chapter will cast one vote, supporting their preferred candidate on the ballot paper, or may abstain from voting. The candidate with the highest number of votes is successful. In the case of a tied ballot, a run-off election between the two tied candidates is held.

D. For election of other commission members, each chapter may nominate up to three eligible candidates. Nominations are not compulsory- chapters may choose not to nominate a candidate or to nominate one, two or three candidates. Each person nominated by a single chapter must be from a different chapter within the region. Persons from the chapter of the newly elected chairperson are ineligible for nomination because each voting member must be a primary member of a different chapter. To be eligible for election, nominees should have served no more than 1 previous voting term on the regional commission. Unsuccessful candidates for the Chair may be nominated if they have not already served 2 voting terms and they are not from the same chapter of the chairperson-elect. A nominated candidate will require support of their own chapter, but not necessarily nomination by their own chapter. The Elections Commission will assemble a full list of eligible nominations, and then from this list provide a slate of up to fifteen candidates on the basis of non-weighted multiple nominations as submitted by the Chapters. Individuals on this list need to agree to stand. If 15 or less nominations are received, then all nominated candidates will appear on the ballot. If several individuals are tied for 15th place, the nominee from the country least represented over the previous term, or if necessary the previous two terms of office, will be selected to stand for election.

E. Each chapter may then cast one vote for each of the elected positions, voting for up to four (or 5) candidates on the ballot paper (dependent on number to be elected in that region) by email, or fax. Each region will determine whether a chapter may choose to vote for less than the number of elected positions, and their vote still be valid, or whether a chapter must vote for a minimum number of candidates in order for their vote to be valid. The decision made must be written into the regional election rules in advance of any election process, and clearly explained on ballot papers. The 4 (or 5, depending on the number of chapters in the region as stated in item 1) candidates with the highest number of votes will be elected. In the case of a tied ballot, preference is given to candidates from chapters that have had the least representation (accounting for all voting members,) over the previous term or, if necessary, the previous two

terms of office. If this fails to break the tie, a run off vote will be carried out.

F. After the election of members is completed, the ILAE President, in consultation with the regional Chairperson-elect, then appoints 2 additional voting members of the regional commission. These appointed members should have served no more than 1 previous voting term.

G. The North American Commission (NAC) requires different consideration as it only consists of three chapters. For this reason, a special committee, named the Regional Selection Committee, will be created. It will consist of five members; one from each chapter (each chapter determining their own selection process), and the past two chairs of the NAC, as long as these individuals do not currently hold office on the ILAE Executive Committee, are not members of the elections committee and are not running for election. If no such person is available then the individual who has most recently served in the ILAE Executive Committee from the region (and is not a candidate) will be included. The chair of the Selection Committee will be the immediate past NAC Chair. The role of the Regional Selection Committee is to create a Regional Commission by selecting the Chair and four elected members. The Commission will consist of 8 members including the 5 newly elected members, the past Chair and two members appointed by the ILAE president in consultation with the elected Chair.

a. To be elected Chair, an individual needs to have served on the regional commission as a voting member for at least one term (4 years) and no more than two terms (8 years). The ILAE Elections Committee will provide to the NAC Regional Selection committee the list of eligible candidates. Individuals on this list then need to agree to stand. Each nominated individual must have support of his or her respective chapter. Each member of the Regional Selection Committee will then vote for one candidate to elect the Commission Chair.

b. Subsequently, to elect the remaining 4 members, each chapter will propose up to 3 candidates for consideration from any chapter in the region. Each nominated individual must have support of his or her respective chapter, and should not have served more than one previous voting term on the regional commission. Based on the full list provided, each of the Regional Selection Committee members will vote for up to four candidates. At least one member of the NAC should be from each of the chapters. In the event of a tie, there will be a run-off vote. The President of the ILAE will appoint two additional voting members to the Commission. This will make a total of 8 voting members including the past chair.

c. Role of the ILAE Elections Committee in the election process for the North American Commission:

i. Notify the 3 chapters to nominate their representative to the Regional Selection Committee and determine their eligibility and willingness to serve. Identify the 2 past NAC chairs eligible to be part of the Regional Selection Committee.

ii. Approve the roster of the Regional Selection Committee according to the guidelines and meetings eligibility criteria.

iii. Confirm the eligibility of the candidates for Chair of the Commission and for the other members of the Commission. The Regional Selection Committee will ensure that the nominees have agreed to run and notify the ILAE Elections Committee that this is indeed the case. Upon completion of the selection process the Regional Selection Committee will notify the ILAE Election Committee which in turn will verify that the process was according to the written by-laws. 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.

iv. The election of the new members of the NAC will completed at the same time as the other regional commissions.

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 report the activities of the executive Committee and ILAE to the chapters through E-mail broadcasts, the ILAE Website, Epigraph and other publications;
 - H. Serve as an ILAE representative on the IBE Executive committee and maintain liaisons with other related organizations;
 - I. Monitor the activities, programs, and developments of ILAE, supporting and promoting policies and programs adopted by the chapters, Executive Committee, and Commissions.
 - J. Provide the leadership for monitoring the ILAE strategic plan;
 - K. Recommend initiatives, research, and special assistance whenever necessary for Executive committee approval;
 - L. Assume a key role in the orientation and transition of the President-elect; M. Identify, recruit and cultivate future leaders of the ILAE;
 - N. Assume other duties and responsibilities as may be assigned by the Executive Committee.
2. The Secretary-General ensures that records are maintained of all General Assembly and Executive Committee Meetings, and encourages chapter development. Specifically, the Secretary General shall:
- A. Serve as a member of the Executive and Management Committee;
 - B. Oversee the maintenance of the official records of ILAE including (i) minutes of regularly called meetings of the General Assembly and Executive Committee; (ii) affiliated chapters in good standing; (iii) official correspondence to and from ILAE and other entities;
 - C. Maintain the Constitution and Bylaws, including responsibility for the process of amending the official documents;
 - D. Give timely notice of all meetings of the General Assembly and Executive Committee;
 - E. Conduct a roll call of the members at the meetings of the General Assembly and Executive Committee meetings, assuring that a quorum is present;
 - F. Promote chapter development and support activities; review applications and supporting documents for the establishment of new chapters and provide guidance to the Executive Committee regarding the approval process;
- G. Serve as an ex officio ILAE representative on the IBE Executive Committee;
 - H. Represent ILAE with other associations or entities as assigned by the President or Executive Committee;
 - I. Receive, process and maintain the reports of Commission and Task Forces, submitting such reports to the Publication Task Force for review, with subsequent recommendation to the Executive Committee for approval for submission to *Epilepsia*, *Epilepsia Open* or *Epileptic Disorders*;
 - 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 Committee;
 - 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 worldwide 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(s)-in-Chief of *Epilepsia* shall be appointed by the executive committee and serve at its discretion, and conduct the day-to-day editorial business of *Epilepsia*. It may be appropriate for the Executive committee to appoint more than one Editor-in-Chief of *Epilepsia*. The editorial content of *Epilepsia* is the responsibility of the Editor(s)-in-Chief. Specifically, the Editor(s)-in-Chief of *Epilepsia* shall:
 - A. Make the final decision on the acceptance or rejection of submitted manuscripts, including reports and documents produced by ILAE Commission and Task Forces and approved by the Executive Committee;
 - B. Make recommendations to the Executive regarding number and role of Associate Editors and Managing Editor;
 - C. Appoint the associate /editors and the members of the editorial Board, and supervise communication with the Board;
 - D. Call meetings of the Editorial Board as needed;
 - E. Recommend an annual budget for *Epilepsia* to the Executive Committee;
 - F. Liaise with the Publisher and oversee compliance with the contract;
 - G. Assists 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 Editor(s)-in-Chief of *Epilepsia Open* shall be appointed by the executive committee and serve at its discretion, and conduct the day-to-day editorial business of *Epilepsia Open*. It may be appropriate for the Executive committee to appoint more than one Editor-in-Chief of *Epilepsia Open*. Currently, the Editor(s)-in-Chief of *Epilepsia Open* serve as invitee non-voting members of the ILAE Executive Committee. Should the constitution be revised, it is recommended that the Editor(s)-in-Chief of *Epilepsia Open* be granted the same privileges and duties pertaining to the Editor(s)-in-Chief of *Epilepsia*.
The editorial content of *Epilepsia Open* is the responsibility of the Editor(s)-in-Chief. Specifically, the Editor(s)-in-Chief of *Epilepsia Open* shall:
 - A. Make the final decision on the acceptance or rejection of submitted manuscripts, including reports and documents produced by ILAE Commission and Task Forces and approved by the Executive Committee;
 - B. Make recommendations to the Executive regarding number and role of Associate Editors and Managing Editor;

- C. Appoint the associate /editors and the members of the editorial Board, and supervise communication with the Board;
 - D. Call meetings of the Editorial Board as needed;
 - E. Recommend an annual budget for *Epilepsia Open* to the Executive Committee;
 - F. Liaise with the Publisher and oversee compliance with the contract;
 - G. Assists the Treasurer in supervising expenditures for the *Epilepsia Open* office
 - H. Perform other tasks as necessary for the operation of, and maintenance of quality, of the journal
10. The Editor(s)-in-Chief of *Epileptic Disorders* shall be appointed by the executive committee and serve at its discretion, and conduct the day-to-day editorial business of *Epileptic Disorders*. It may be appropriate for the Executive committee to appoint more than one Editor-in-Chief of *Epileptic Disorders*. Currently, the Editor(s)-in-Chief of *Epileptic Disorders* serve as invitee non-voting members of the ILAE Executive Committee. Should the constitution be revised, it is recommended that the Editor(s)-in-Chief of *Epileptic Disorders* be granted the same privileges and duties pertaining to the Editor(s)-in-Chief of *Epilepsia*.

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

- A. Make the final decision on the acceptance or rejection of submitted manuscripts, including reports and documents produced by ILAE Commission and Task Forces and approved by the Executive Committee;
- B. Make recommendations to the Executive regarding number and role of Associate Editors and Managing Editor;
- C. Appoint the associate editors and the members of the Editorial Board, and supervise communication with the Board;
- D. Call meetings of the Editorial Board as needed;
- E. Recommend an annual budget for *Epileptic Disorders* to the Executive Committee;
- F. Liaise with the Publisher and oversee compliance with the contract;
- G. Assists the Treasurer in supervising expenditures for the *Epileptic Disorders* office
- H. Perform other tasks as necessary for the operation of, and maintenance of quality, of the journal.

- 11. 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*, *Epilepsia Open* and *Epileptic Disorders*

Epilepsia, *Epilepsia Open* and *Epileptic Disorders* are the journals of the International League Against Epilepsy (ILAE).

Epilepsia publishes original articles on all aspects of epilepsy, clinical and experimental. The journal also publishes timely reviews, as well as commission and task force reports from various ILAE groups.

The mission of *Epilepsia Open* is to make original research on all aspects of epilepsy widely available through open access publication, and to give wider representation to the ILAE constituency.

Epilepsia Open also addresses the need to provide a publication forum for early, preliminary studies on epilepsy that may provide new directions for clinical and laboratory research including negative and confirmatory studies. *Epilepsia Open* also publishes commission and task force reports from various ILAE groups.

The mission of *Epileptic Disorders* is to create educational links between epileptologists and other health professionals in clinical practice and scientists or physicians in research-based institutions. *Epileptic Disorders* also publishes commission and task force reports from various ILAE groups.

- 1. The Editorial Advisory Boards of *Epilepsia*, *Epilepsia Open* and *Epileptic Disorders* shall consist of all members of the Executive Committee, except for the Editor(s)-in-Chief. It advises the editors on matters of general policies and arbitrate on matters referred to it by the Editor(s)-in-Chief, but shall leave the day-to-day conduct of the journal entirely to the Editor(s)-in-Chief and the Editorial Board. The editorial content of *Epilepsia*, *Epilepsia Open* and *Epileptic Disorders* is the responsibility of the respective Editor(s)-in-Chief.
- 2. The Executive Committee shall approve or terminate any contract with the publisher(s). It shall determine the budget of the journals.
- 3. The Editor(s)-in-Chief will take all steps necessary to fulfil the aims of ILAE as it pertains to the mission of the journals.
- 4. 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 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.

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 of elected officers, 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 VIII – 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.

Article X – Endorsement of guidelines

1. The ILAE will not endorse guidelines/reports of other organisations unless the League is officially participating in their development from the outset.

Article XI – Regions

1. Regional Commissions should meet from one to three times a year and must submit an annual budget for approval to the Executive Committee.

2. Regional Commissions should aim to develop, stimulate and coordinate the epileptology agenda in their part of the world.
3. Regional Commissions should promote the activities of local chapters, encourage similar policies and administrative structures and facilitate their involvement within the global ILAE agenda.
4. Regional commissions can have designated funds which they access via the budget process.
5. Regional Commissions should coordinate local educational activities.
6. Regional Commissions should run their congresses under the direction of the International Director of Meetings.
7. 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.
8. Regional Commissions should develop documents with the aim of stimulating local medicopolitical initiatives and improving patient care.
9. Chapters can belong to only one region.
7. Chairing of each JEC shall be shared equally between the ILAE and IBE Presidents, or their nominees, in a manner acceptable to both. The Chairperson of a JEC shall not have a casting (i.e., tie-breaking) vote.
8. A quorum for a JEC shall be the presence of a majority of the members of each of the ILAE and IBE Executive Committees.
9. A JEC may be convened at any time mutually acceptable to the Presidents of both the ILAE and IBE.
10. To be considered by a JEC, a motion must be moved by a member of one Executive Committee, and seconded by a member of the other.
11. Responsibility for administration, minuting etc. of JECs shall be shared equally between the Secretaries-General of the ILAE and IBE, in a manner acceptable to both.
12. Responsibility for overseeing all financial matters considered by JECs shall be shared equally between the Treasurers of the ILAE and IBE, in a manner acceptable to both.

Article XII – 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.

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 XIII – 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.