

ILAE: The Next Generation

2018 Annual Report



INTERNATIONAL LEAGUE AGAINST EPILEPSY



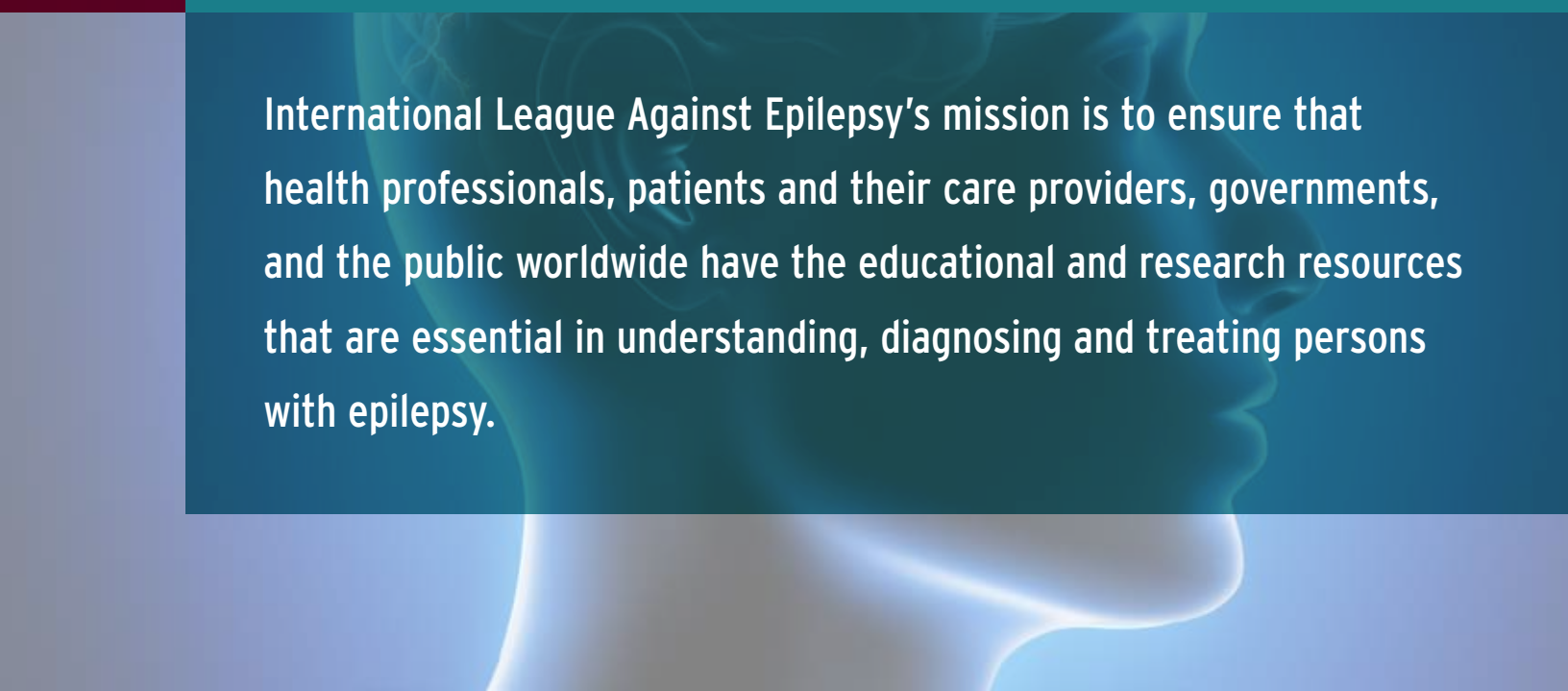
OUR VISION



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



Samuel Wiebe

The completion of my first full year as President of the ILAE is a fitting moment for reflection. Are we taking the necessary steps towards achieving our vision? Are we making the most of new opportunities? What are the challenges ahead and how are we responding? The balance of this year's activities is a strong indicator that we are off to a strong and productive start. I highlight below some of the salient developments from 2018.

Education:

Years of consultation and planning have culminated in the creation of a competencies-based curriculum for epilepsy, with three levels of proficiency or expertise, i.e., basic, medium, and advanced. Under the leadership of Dr Ingmar Blümcke, dedicated staff with expertise in distance learning have been recruited to help us create our own case-based online teaching modules. We are building a strong partnership culture in education by joining efforts with other organizations that share our educational aims. For example, we now partner with the International Federation of Clinical Neurophysiology (IFCN) for education in EEG. We are exploring partnerships with eBrain (www.ebrain.net) to adapt and use some of their eLearning materials and courses. We have a formal partnership agreement with BPNA for PET courses (www.bpna.org.uk/pet), which are now offered not only in Europe, but also in Africa, Asia and Latin America. We continue to partner with the World Federation of Neurology to deliver the epilepsy educational programme at the World Congress of Neurology. In addition, we continue to support the increasingly popular international courses on Neuropathology, Neuropsychology, EEG and Imaging. Finally, the highly popular ILAE online educational tool for epilepsy and seizure classification (EpilepsyDiagnosis.org) has been revamped and revised to include the new ILAE definitions and nomenclature, under the direction of Dr. Kate Riney.

Our Journals:

Thanks to our outstanding editorial teams, the solid development of our three journals continues. *Epilepsia* maintains a milestone impact factor of five or higher. *Epilepsia Open* was accepted in Pubmed Central in March 2018, and all of its articles are now in Pubmed. *Epileptic Disorders* has a new

co-Editor, Dr Sándor Beniczky, and is refining its focus as the prime educational journal of the League. We continue to learn about the intricacies and opportunities of *Wikipedia-Epilepsy*, and we are making gradual but steady gains under its new editor, Dr. Nicola Maggio.

The Next Generation:

At the outset, one of my main goals was to engage the younger generations of epilepsy professionals in a meaningful way, and so we created the "Next Generation" Task Force, chaired by Dr. Helen Cross. Under the umbrella of this Task Force, three initiatives have flourished, all primarily led by Dr Helen Cross:

- 1) YES (Young Epilepsy Section): A dynamic and effective group of professionals under 40, whose aims are to improve the professional development of young people in epilepsy, and to deepen the participation of young people in the ILAE. You can learn more at <https://www.ilae.org/about-ilae/topical-commissions/young-epilepsy-section-yes>.
- 2) The Mentor-Mentee Programme: This takes place at ILAE congresses and provides an opportunity for interaction between individuals in the early stages of their careers and seasoned epilepsy professionals, with the aim of sharing experiences that can inform the careers of the next generation of epileptologists.
- 3) The Leadership Development Program: This highly successful, intensive programme is aimed at individuals in their early-mid career who are taking on leadership roles in their own region. Led by Drs Sheryl Haut and Jaideep Kapur, it takes place over two days at our International Congress and is now being deployed in our Regional Congresses.

ILAE Congresses:

Our International and Regional Congresses must serve two important purposes. First, they need to be of the highest scientific standard. Second, they need to provide for the educational needs of our constituency. Accordingly, we are rethinking how the congresses are organized, in order to optimize both the scientific and the educational aims, and to align the learning opportunities with our Epilepsy Curriculum. Dr Helen Cross is leading this effort.

President

Regional Executive Board:

The Chairs of the six Regional Commissions and the Management Committee held a very productive strategic retreat in June 2018. This new exercise was extremely fruitful and will be repeated annually. The purpose is to review strategic aims, inform our decisions for financial support, assess progress, and share knowledge and experiences. Our six Regional Commissions have new names. For example, the “Commission on African Affairs” now has the nimbler and more descriptive name “ILAE-Africa”; the same applies to all Regions: ILAE-Asia, ILAE-Eastern Mediterranean, ILAE-Europe, ILAE-Latin America, and ILAE-North America.

Communication:

Dr Ed Bertram leads the Communications Task Force, and Dr Jean Gotman leads the Publications Task Force and the ILAE’s website development. It became evident that we needed to improve our communications within the ILAE constituency, and importantly, with the community-at-large. Accordingly, a dedicated writer has been recruited specifically to develop written material pertaining to ILAE activities that can be published widely; both online and in other media.

Global Outreach:

We continue to collaborate with the World Health Organization (WHO) in far-reaching activities. Stemming from the 2015 resolution of the World Health Assembly to prioritize epilepsy, a new WHO Global Report in Epilepsy is being created jointly by the WHO, ILAE, and IBE. Under the leadership of Dr Alla Guekht, the Global Outreach Task Force is a major driver of this initiative, and of current engagement with the WHO toward developing a Global Strategic Plan for Epilepsy.

Finances:

We continue to benefit from the invaluable help of our Finance Advisors to manage our finances wisely. As stated by our Treasurer, Dr Helen Cross, we continue to navigate the unpredictability of the stock market with invaluable expert assistance, to ensure that the League’s finances are in good shape. We are approaching our endowment investment target. This will allow us to support targeted activities which we will choose strategically with input from our Regional Executive Boards.

Commissions and Task Forces:

Our many commissions and task forces dealing with specific topics have established a course of action during the first year. Numerous projects are underway, and they will come to fruition over the next few years.

Throughout this report, I have named a few of the leaders responsible for the progress we have made this year. However, the efforts are multitudinous. The League is truly fortunate to have such a dedicated group of colleagues and friends working towards a common goal. To all who have devoted their wisdom, time and energy to our cause over the course of the year, I express my deepest gratitude and appreciation.

Samuel Wiebe
President

Treasurer

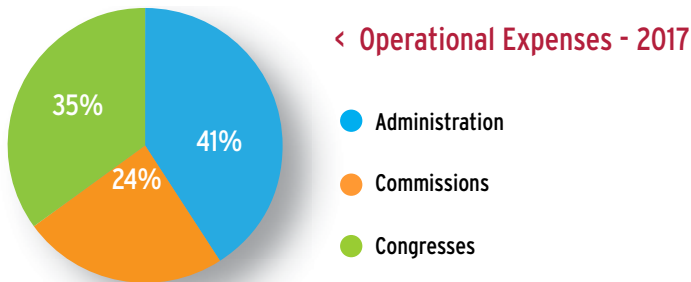
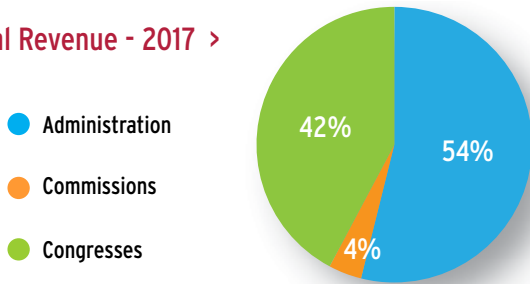


J. Helen Cross

As we come to the end of the second year of this term, we remain in good shape financially. The challenge remains how to preserve our endowment to enable increased support of mission-driven initiatives. However, although our current position has enabled us to invest in our educational mission and communications, we also have to be aware of the fluctuating markets, and therefore to show a little more fiscal responsibility over the coming year with regard to our budget

The chart below shows the final audited results for 2017. Administrative revenue, the largest portion, was primarily generated from our publication royalties. Registrations, exhibitors, and sponsors made up the congress revenue, while most of the commission revenue came from registrations for courses targeting specific topics in epilepsy.

Operational Revenue - 2017 >



Illustrated above are the offsetting expenses with surpluses evident for both the congresses and administration. The surpluses from these two categories support the important work done by our commissions and task forces, including

courses, workshops, fellowships, and other projects. The year concluded with a positive net change for operations, as well as very good investment earnings; the result of a strong stock market.

The League's strong financial position continued into 2018. Administrative expenses decreased as the result of a change from a managed to a self-managed administration model. We also decided to invest in communications and hired a writing specialist. Additionally, the development of an epilepsy curriculum continues with plans to launch a pilot program at the beginning of 2019. Our strong commitment to the commissions and task forces is also maintained with increased budgets for both 2018 and 2019.

In June 2018, as recommended by our Financial Advisory Committee, a new investment firm, Goldman Sachs, was engaged to manage our portfolio in accordance with our investment policy. Shortly after this change, the stock market was subject to extreme volatility and uncertainty. However, given our diverse portfolio and with the guidance of our volunteer advisory group, our investment losses were manageable, although reaching our endowment goal has been slightly delayed. Despite the losses experienced at the end of 2018, when the financial audit is complete, we expect a break-even year end.

We are grateful to the commissions and task forces for their ongoing work toward meeting our mission and goals. The budgets submitted took careful thought and planning; we have tried to allocate and approve a substantial portion of what was requested, although we have had to be a little more frugal than in previous years. This aside, we hope as we move through the coming year, our position will become stronger, in order for us to reconsider further additional projects next year.

As ever, we are also grateful to the budget committee that worked hard over the holiday period to review all budgets, as well as to our group of financial volunteers who advise us via the Financial Advisory Committee.

J. Helen Cross,
Treasurer

Vice President



Alla Guekht

The main areas of activity in 2018 were WHO-related issues, including global outreach; a number of activities had been implemented in collaboration with the ILAE Global Outreach Task Force.

Along with the historical acceptance of the 68th WHA Resolution on Epilepsy, several important milestones had been reached in 2018. The ILAE was represented at a number of global WHO events, where numerous presentations, meetings, and discussions were scheduled in order to strengthen the positioning of epilepsy as a public health priority.



*Statement on epilepsy
(Alla Guekht)*

At the 71th World Health Assembly (WHA) in May 2018, the scheduled WHO report on the implementation of the 68th WHA Resolution on Epilepsy was presented. The ILAE closely collaborated with WHO and greatly appreciated the important developments achieved since 2015 in promoting epilepsy awareness, care, and research. Significant collaborative initiatives of the WHO, ILAE and IBE remain in progress. However, the implementation of the Resolution is far from complete, and the response to the global burden of epilepsy should be greatly enhanced by a shared commitment among member states and all other stakeholders to put in place the necessary policies and resources for care of people living with epilepsy, to promote further research, and to give adequate priority to action against epilepsy in both national and global political agendas. According to the extensive communications with a number of member states, statements were made by the Russian Federation, Honduras, Zimbabwe, and China (thanks to Marco Medina, Shichuo Li, and Jacob Mugumbate). There were also statements from the World Federation of

Neurology (WFN), the ILAE, and IBE. Statements may be found at <https://extranet.who.int/nonstateactorsstatements/meetingoutline/6>. There are three core requests in these statements: extension of the implementation of the resolution and report at the 74 WHA, a global action plan, and the inclusion of an epilepsy item in the 144 WHO EB Agenda.



*With the Minister of Health
of Honduras,
Dr. Octavio Rubén
Sánchez Midence*

These requests were also highlighted during the informal side event on May 22. The discussion at the side event addressed several important items: how public health policy must shift to help people living with epilepsy achieve a better quality of life, and what the global accomplishments and remaining challenges associated with the resolution on epilepsy are.

*At the 71th WHA,
following the statements
provided by the WFN
(President William
Carroll), ILAE (Vice
President Alla Guekht)
and IBE (Member of the
GOTF, Jacob Mugumbate)*



The UN High-Level meeting on Non-Communicable Diseases (NCDs) (September 23) was a prominent event, where many heads of state and Ministers of Health of the member states demonstrated their commitment to combating NCDs. A new and very important concept was presented - the fifth domain of the NCDs (in addition to the existing four - cardiovascular diseases, cancers, respiratory diseases, and diabetes), which covers a number of brain/mental health diseases including epilepsy, depression, dementia, and some

Vice President *(continued)*

other neurodegenerative disorders. Epilepsy as a part of this 5th domain was announced in the official interviews. A number of the principal ILAE activities were planned based on this concept, including increasing collaboration with the World Federation of Neurology and the World Stroke Organization.

At the mh-GAP forum “Accelerating Country Action At the mh-GAP forum “Accelerating Country Action on Mental Health” (October 11-12) a supportive statement with the above-mentioned three requests was presented by the Russian Federation. A number of important meetings took place, including a meeting with the WHO Assistant DG on NCDs, Dr. Svetlana Akselrod, and the newly appointed Director of the Department of Mental Health and Substance Abuse, Devora Kestel.

Preparation for the 144 WHO Executive Board (EB) meeting (January 2019) was an important part of the 2018 activities.

As mentioned, in order to escalate the implementation of the 68th WHA Resolution on epilepsy and to initiate the preparation of the Global Action Plan on epilepsy, it was mandatory to include the item “Further actions to address the global burden of epilepsy and its health and social implications at the country level” into the agenda of the 144 WHO Executive Board (EB) in order to: develop a global action plan for epilepsy and to prepare a new report on the implementation of the WHA Resolution 68.20, to be discussed at the 74th WHA in 2021. Accordingly, it was essential to obtain support from the EB members for this request. After extensive communication with the ILAE and the IBE regional and chapter leadership, official letters to the WHO Secretariat were submitted by Croatia, Honduras, Romania, and Philippines (thanks to Silvio Basic, Marco Medina, Dana Craiu and Leonor Cabral Lim). However, the item was not included in the 144 WHO EB Agenda, so the Russian Federation agreed to raise this issue on-site at the WHO EB meeting, and support from the countries/ EB members was needed. In order to achieve this, a second round of extensive communication with the epilepsy community was initiated and eventually, in January 2019, the goal was reached with the outstanding support from the Russian Federation, China, Chile, Jamaica, and Indonesia (to be presented in detail in the 2019 report).



Alla Guekht with Dr. Svetlana Akselrod, the WHO ADG, and the Russian Delegation at the High-Level UN meeting.

A new initiative - Epilepsy Education for the WHO staff - was successfully implemented in 2018. The ILAE contributed to the capacity building programme for WHO’s National Professional Officers (NPOs) working at WHO’s Country Offices (Lausanne, December 2018). The lecture, with essential information about epilepsy, the burden of the disease, and the key strategies to improve the care and quality of life of people with epilepsy, was included in the programme. The feedback from the organizers and participants was very positive, so this initiative will be further developed.

In light of the growing role of non-communicable diseases (NCDs) as a global public health priority, the reinforcing of the profile epilepsy as a NCD proved to be highly significant. Political declaration of the third high-level meeting of the UN General Assembly on the Prevention and Control of Non-communicable Diseases A/RES/73/2 18-16893 3/7 recognized that mental disorders and neurological disorders contribute to the global burden of non-communicable diseases, and that people living with these conditions face stigma and discrimination, being more susceptible to human rights violations and abuse, as well as having an increased risk of other non-communicable diseases, and therefore higher rates of morbidity and mortality. In fact, epilepsy belongs to the category of non-communicable diseases; furthermore, it is often comorbid

Vice President *(continued)*



Statement at the mh-GAP Forum.

to a number of other somatic and psychiatric conditions; a bi-directional association has been established between epilepsy and depression, cerebrovascular disease, stroke, and dementia.

Accordingly, a collaboration with the WHO European Office for the Prevention and Control of Noncommunicable Diseases was established, with several productive meetings with the head of this office, Dr. João Breda. A session on epilepsy, with participation from the ILAE leadership and the head of the WHO European Office for the Prevention and Control of Noncommunicable Diseases, was organized in the framework of the conference, “Advances in neuroscience, and new strategies for preventing and treating brain diseases,” in November 2018.

A collaboration with the World Federation of Neurology, European Academy of Neurology (EAN), and the World Stroke Organization (WSO) was significantly reinforced in 2018. The WFN extensively supported the ILAE at the 71 WHA; and the WFN and the EAN addressed the WHO Secretariat, with the request to include epilepsy item in the 144 WHO EB Agenda. Joint efforts in the prevention and treatment of post-stroke epilepsy were discussed with the leadership of the WSO.

Global Epilepsy Report (GER) is the collaborative endeavour between the WHO, ILAE and IBE. The objective of the document was to raise awareness on the

global burden of epilepsy and the possible approaches to addressing the epilepsy treatment gap at the country level, especially for low- and middle-income countries. It provided information and guidance on approaches for improving policies, plans, and programmes, and their implementation. The goal was to enhance awareness about the global problem of epilepsy and its response, in order to encourage countries to improve access to epilepsy care at the community level and hence, improving the social well-being and quality of life of people with epilepsy and their families.

The report includes:

- ♦ An executive summary
- ♦ The global burden of epilepsy
- ♦ Leadership, governance, policy, plans, and programs for epilepsy
- ♦ Healthcare response
- ♦ Access to anti-seizure medications
- ♦ Stigma and misconceptions – the social response
- ♦ Prevention of epilepsy
- ♦ Research on epilepsy
- ♦ Way Forward

Vice President *(continued)*



At the GER Advisory Committee meeting in Paris in July 2018.



The faculty of the ILAE-IBE side event on May 22, during the 71 WHA.

The Steering Committee invited more than 40 leading epilepsy professionals and representatives of the IBE to contribute to the document. There were many impressive developments this year, from the raw concept to the harmonization of the nearly completed document. Several important and productive meetings were arranged, including the GER Advisory Committee meeting in July 2018, and the Project Coordinating and Editing Group meeting in September 2018.

Other important accomplishments in 2018 included the active participation in the Executive Committee and the

Management Committee meetings, along with involvement in several key domains, including communication and education, and participation as the ILAE Management Committee liaison in the work of the ILAE commissions and task forces: ILAE-Europe Board, Driving Task Force, Psychiatry Commission, Global Health Task Force, and others.

Alla Guekht
Vice President



Astrid Nehlig



Michael Sperling

In 2018, *Epilepsia* had another successful year. In bibliometric terms, in 2018, *Epilepsia* was ranked 24th of 197 journals in the Clinical Neurology category, had an Impact Factor (IF) of 5.067, an h-index of 168 and an Eigenfactor of 0.041. After a steady increase of *Epilepsia's* IF over five years (from 4.584 in 2013 to 5.295 in 2016), in 2017, the IF of *Epilepsia* slightly dropped to 5.067. It remains higher than that of any of the other epilepsy sub-specialty journals, with the exception of *Epilepsy Currents*, which does not publish original research, and publishes AES guidelines and review articles (IF for 2017: 9.333). The objective in recent years was to try to improve journal quality and increase the impact factor to 5.0. Achieving this IF will attract higher quality publications, mainly in basic science and especially from Europe. This goal has now been achieved, and the objective is to continue improving quality and, hopefully, raising the IF further.

Volume 59 (calendar year 2018) comprised 2,764 printed pages and 165 e-only pages, which included twelve regular monthly issues.

The following supplements were also published:

- ♦ **S1: Seizure detection and mobile health devices in epilepsy:** Update and future development, 68 pages, – Philippe Ryvlin and Sándor Beniczky, guest editors;
- ♦ **S2: A decade of progress in status epilepticus, 2007-2017:** Proceedings of the 6th Colloquium on Status Epilepticus and Acute Seizures, 248 pages, – Eugen Trinka and Simon Shorvon, guest editors;
- ♦ **S3: Special Issue: Abstracts of the 13th European Congress on Epileptology,** Vienna, Austria, 26-30 August 2018, 225 e-only pages.

Epilepsia Statistics for 2018

Number of manuscripts submitted and accepted for each category of papers published in the journal..

Manuscripts submitted and accepted in 2018

	Total number of manuscripts	Reviews	Full length original research articles	Brief communications	Special reports (ILAE Commissions)	Letters
# submitted	1123	33	836	207	8	18
% accepted	28.6%	35.7%	17.2%	9.7%	50.0%	100%

Manuscripts rejected in 2018

Decision	Percentage
Direct reject	36.4%
Direct reject with transfer to EO	23.1%
Direct reject with transfer to EPD	5.6%
Direct reject with resubmission option	2.0%
Reject after review	21.0%
Reject after review and transfer to EO	3.4%
Reject/resubmit after review	8.4
TOTAL	100%

The editors consider quality and novelty as the most important criteria when choosing papers for publication. The journal has a diverse audience, and the editors view the need to appeal to a wide range of readers as critical. Financially, the Journal remains highly successful, bringing in net income to ILAE of over US\$1 million.

In terms of circulation and readership in 2018, 6,842 institutions offered access to *Epilepsia*, either through a license or a traditional (title-by-title) subscription. Licensed subscriptions grew by 11%, from 6,036 to 6,736. The increase in licensed access typically means a decrease in title-by-title subscriptions. In 2018, traditional subscriptions dropped by 5%, from 80 to 76. In addition, Hinari philanthropic initiatives extended low-cost or free access to current content in 2018 to 7,669 developing world institutions.

In 2018 there were 1,859,510 full-text downloads of *Epilepsia* content, a 5% decrease over the preceding year. Wiley advised us that in September 2018, they became aware of a decline in the number of full-text downloads in Wiley

Online Library usage data since July 2018. The decrease was due to a change that was made in Google Scholar, which directed users to the abstract of the article, rather than to the full text of the article, as was previously the case. On October 10, Wiley implemented a redirect in Wiley Online Library, which sent authenticated users via Google Scholar and all the major search engines directly to the full text HTML version of the article.

Although figures for full-text downloads are lower, Wiley does not believe that readership of *Epilepsia* will have been seriously impacted. Researchers still reached the paper they were looking for and, once on the abstract page, were able to download full-text HTML or PDF versions if they wished. Wiley fully expects the number of downloads to continue to rise, and will provide more detail in their 2018 full publisher report.

Astrid Nehlig and Michael Sperling
Editors-in-Chief, *Epilepsia*



Aristeia Galanopoulou



Dong Zhou

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Aims

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.

Mission

The 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.”

Commission activities (2018)

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 2018, ECE Vienna, AES meeting at New Orleans in 2018) to discuss the progress, strategies, and action items, and advance the quality and visibility of the Journal. The editorial board of the Journal changed in September (see editorial board list). Two new special issues were published (see accomplishments).

Accomplishments (2018)

Editorial Board: A new editorial board team assembled under the leadership of Drs Aristeia Galanopoulou and Dong Zhou for a two-year term, which includes experts from various countries and of diverse backgrounds, including clinical, basic science, and statistical expertise.

Marketing and increasing awareness of the Journal: Wiley continued an extensive marketing strategy to regularly highlight the content of the Journal's issues, and target both basic and clinical scientists and epilepsy professionals through regular newsletters. Selected articles from the Journal's issues are also highlighted in the ILAE website and in ILAE newsletters. In parallel, the Editors-in-Chief have been flexible in providing waivers of the APCs when asked, to increase awareness of the Journal, and facilitate submissions from authors who would have difficulty meeting the publication fee requirements.

As a result of these efforts, there has been an increased number of article downloads (~44,500 in 2018 vs. ~29,000

in 2017 vs. ~7,500 in 2016), ~23,000 unique visitors to the website from a diverse range of countries, including but not limited to the USA, United Kingdom, India, China, Canada and Germany.

Epilepsia Open Prizes: We initiated the selection of new annual awards to recognize the best basic and clinical original science articles published in *Epilepsia Open* by young investigators. Selection of the awardees was conducted through editorial board voting. The first *Epilepsia Open* Prize for Clinical Research was awarded to Dr. Carla Bentes (North Lisbon Hospital Center, Lisbon, Portugal) for the article “Seizures, electroencephalographic abnormalities, and outcome of ischemic stroke patients” (<https://onlinelibrary.wiley.com/doi/10.1002/epi4.12075>). Dr Bentes received her prize at the 13th ECE in Vienna. The first *Epilepsia Open* Prize for Basic Science was awarded to Dr Jiang Li for her article, “Disrupted female estrous cyclicity in the intrahippocampal kainic acid mouse model of temporal lobe epilepsy” (<http://onlinelibrary.wiley.com/doi/10.1002/epi4.12026/full>). Dr Li received her prize at American Epilepsy Society’s annual meeting in New Orleans, LA, USA.

Published issues: In 2018, *Epilepsia Open* published four quarterly scheduled issues (Volume 3, Issues 1-4), each including 10-20 articles. In addition, two special issues were published.

The first special issue (Volume 3, S1) included reports from the TASK3 group of the ILAE/AES Joint Translational Task Force on preclinical epilepsy common data elements. Guest editors were Drs Aristeia Galanopoulou, Helen Scharfman, Lauren Harte-Hargrove, Jacqueline French, Vicky Whittemore and Asla Pitkänen. In addition, a request for community feedback was made through the ILAE, AES, NINDS, and CURE (deadline set to January 15th, 2019). The second special issue (Volume 3, S2) was guest edited by Drs Andrey Mazarati and Solomon L. Moshé in honor of Dr Raman Sankar, and had an overall theme of epilepsy therapies. A list of prominent authors contributed to this

issue, and included basic, clinical, and translational articles. *Submissions:* There has been an increasing and steady flow of submissions to *Epilepsia Open*. These are coming from two sources: transfers from *Epilepsia* and direct submissions. In 2018, most submissions were direct submissions (62.5% vs 31.5% in 2017). Among the manuscripts offered a transfer from *Epilepsia*, ~15% result in submissions to *Epilepsia Open*.

In 2018, submitting authors originated from 26 countries; leading submitting countries were the USA (34%), Japan, UK/Northern Ireland, China, Canada, Netherlands (4.7-6.4%), and India, Italy, Australia, Finland, Germany, France, Ireland, and Hong Kong (2.1-4.6%). Leading publishing countries, after consideration of those with accepted publications, included the USA (38.4%), Canada, UK/Northern Ireland, Italy, Netherlands, Japan (4.3-6.7%) and China, Finland, Germany, Ireland and Australia (2.4-4.2%). The majority of the submitted articles are full-length original research or short research reports, followed by critical reviews or commentaries. Clinical articles comprised 58.3% of submissions, followed by basic science with 22% and translational research with 16.7%.

Processing and production times: The average time in peer review is currently 49.3 days, with an average review time for original or revised articles ranging between 11.7 and 9.3 days respectively. The acceptance rate is currently 83.8%. From the time an article is accepted, it usually takes 5.7 days to appear online as an accepted article and 41 days to appear as an early view.

Citations: An increasing number of articles are getting cited with the nine top cited ranging between 5-25 citations/article. *Epilepsia Open* (launched in September of 2016) is too young to have an impact factor, however, based on the rate of citations, we expect that it will have a strong impact factor when it is ready to receive one.

Indexing: The application for the Directory of Open Access Journals (DOAJ) has been approved and, as of March 2018, the application for PUBMED Central (PMC) inclusion was

also approved. In December 2018, *Epilepsia Open* was also accepted in the Scopus database. Currently, most *Epilepsia Open* articles have appeared in the Pubmed. An application for EMBASE has been submitted, and we plan to apply for ESCI and Medline.

Recommendations for Future Work

Applications for inclusion to databases: We plan to apply for ESCI and Medline while the decision for EMBASE is pending.

Marketing: Planned marketing campaigns include 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 countries from all continents using these marketing tools.

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) maintain the number of basic and translational science article submissions at high levels; and

- (5) re-evaluate the needs and thematic priorities of our journal so that it becomes competitive in the field of epilepsy publications.

Aristea Galanopoulou
Co Editor-in-Chief

Epileptic Disorders

Editors-in-Chief

Alexis Arzimanoglou
Sándor Beniczky

Associate Editors

Ingmar Blümcke
Michael Duchowny
Yushi Inoue
Philippe Kahane
Michalis Koutroumanidis
Rüdiger Köhling
Lieven Lagae
Doug Nordli
Guido Rubboli
Graeme Sills
Mary Lou Smith
Pierre Thomas
Torbjörn Tomson

2018 Published Manuscripts

	No. submissions	% Final decisions		
		Accepted	Rejected	Directly rejected
2016	150	39	41	20
2017	143	46	36	18
2018	163	53	30	17

In 2018, Epileptic Disorders saw a number of changes. Regarding the Editorial Board, in September, the current Editor-in-Chief, Alexis Arzimanoglou, was joined by Sándor Beniczky, and they now share the role of Editor-in-Chief. In addition, Rüdiger Köhling and Mary Lou Smith were welcomed as additions to the team in the role of Associate Editors.

We also thank Aristeia Galanopoulou, Alexander Hammers, and Sarah Wilson for their significant input as Associate Editors over the past few years.

In 2018, 76 manuscripts were published in 6 two-monthly editions; these included 13 manuscripts with free access and four with open access. There has been a modest increase in the number of submissions, with 163 manuscripts submitted in 2018 (see above).

In February 2018, the journal became available in electronic format only, and this is reflected in a substantial increase (55%)

in the number of visitors to the Epileptic Disorders website (www.epilepticdisorders.com). The website is run by the publishing company, John Libbey Eurotext. This increase in visitors is very encouraging, as we are in the process of further developing the site as a platform for education/teaching material. Included is a video library that has been significantly improved to be as user-friendly as possible, with better search functionality and display of the educational video collection.

Newsletters (highlighting papers of interest), new content and ILAE announcements continue to be regularly diffused to an extensive emailing list by John Libbey Eurotext, with the aim of reaching the largest possible audience within the epilepsy community.

Epileptic Disorders (continued)

Manuscripts with the most hits on the Epileptic Disorders website in 2018

TITLE	AUTHORS
The 2017 ILAE classification of seizure types and the epilepsies: What do people with epilepsy and their caregivers need to know?	Martin J. Brodie, Sameer M. Zuberi, Ingrid E. Scheffer, Robert S. Fisher
Crossing the lines between epilepsy syndromes: A myoclonic epilepsy variant with prominent eyelid myoclonia and atonic components	Pinelopi Dragoumi, Jacqueline Emery, Fiona Chivers, Megan Brady, Archana Desurkar, J Helen Cross, Krishna B Das
Epilepsy surgery for patients with genetic refractory epilepsy: A systematic review	Remi Stevelink, Maurits WCB. Sanders, Maarten P. Tuinman, Eva H. Brilstra, Bobby PC. Koeleman, Floor E. Jansen, Kees PJ Braun
Sleep-related hypermotor epilepsy activated by rapid eye movement sleep	Xiaoli Wang, Lara V Marcuse, Lang Jin, Ying Zhang, Wenjuan Zhang, Beibei Chen, Na Yuan, Bi Wang, Yonghong Liu
Rufinamide for the treatment of Lennox-Gastaut syndrome: Evidence from clinical trials and clinical practice	Pasquale Striano, Rob McMurray, Estevo Santamarina, Mercè Falip
Epileptic seizure semiology in different age groups	Guadalupe Fernandez-Baca Vaca, Carlos L. Mayor, Naira García Losarcos, Jun T. Park, Hans O. Lüders
Facing the hidden wall in mesial extratemporal lobe epilepsy	Tom Theys, Thomas Decramer, Wim Van Paesschen, Xavier De Tiège, Lorella Minotti, Marec von Lehe, Stephan Chabardès, Philippe Kahane, Anne-Sophie Job
Ictal laryngospasm monitored by video-EEG and polygraphy: A potential SUDEP mechanism	Nuria Lacuey, Laura Vilella, Johnson P. Hampson, Jayakumar Sahadevan, Samden D. Lhatoo
Somatosensory reflex epilepsy: Simultaneous video-EEG monitoring and surface EMG	Kyoung Jin Hwang, Dae Won Seo, Seong Bong Hong, Eun Yeon Joo
Genetic literacy series: Genetic epilepsy with febrile seizures plus	Kenneth A. Myers, Ingrid E. Scheffer, Samuel F. Berkovic
A comparison between the 1981 and 2017 International League Against Epilepsy classification of seizure types based on an outpatient setting	Hui Gao, Josemir W. Sander, Yingfeng Xiao, Yingying Zhang, Dong Zhou
Unilateral abdominal clonic seizures of parietal lobe origin: EEG findings	Danah Aljaafari, Fábio A. Nascimento, Alon Abraham, Danielle M. Andrade, Richard A. Wennberg
Identifying the educational needs of physicians in pediatric epilepsy in order to improve care: Results from a needs assessment in Germany, Spain, and the United States	Suzanne Murray, Sara Labbé, Sanjeev Kothare, Ignacio Málaga, Gerhard Kluger, Patti Ogden, Patrice Lazure, Alexis Arzimanoglou
Idiopathic generalised epilepsies of adult onset: A reappraisal and literature review	José Pimentel, Sara Varanda, Pedro Guimarães, Fernando Lopes da Silva
Probable dysimmune epilepsia partialis continua manifesting as epileptic moving toes syndrome: Electroclinical features of a challenging case	Francesco Brigo, Alberto Vogrig, Arianna Bratti, Veronica Tavernelli, Raffaele Nardone, Eugen Trinka

The content of the journal is also regularly promoted on the ILAE website. Together with *Epilepsia* and *Epilepsia Open*, it is also available on the Wiley Online Library (<https://onlinelibrary.wiley.com/journal/19506945>).

Wiley also diffuses the best articles published in *Epileptic Disorders* in its monthly ILAE Newsletter.

The 5 most accessed articles published in 2018 were:

- The 2017 ILAE classification of seizure types and the epilepsies: What do people with epilepsy and their caregivers need to know?
- Epileptic seizure semiology in different age groups
- Facing the hidden wall in mesial extratemporal lobe epilepsy
- Genetic literacy series: Genetic epilepsy with febrile seizures plus
- Idiopathic generalised epilepsies of adult onset: A reappraisal and literature review

The format of *Epileptic Disorders* has remained essentially the same, and the Journal continues to publish Original Articles (45%) and Clinical Commentaries (41%), in addition to the more didactic Reviews (6%), Seminars in Epileptology (2%), Clinical Reasoning Reports (3%), and Multimedia Teaching Material (3%) (percentages for 2018).

The **Review** and **Seminar in Epileptology** series remains a priority in line with the remit of the journal, as the educational journal of the ILAE. Free access is available for both.

Review articles reflect novel findings and state-of-the-art techniques, targeting an audience of specialists in epileptology, and are directly relevant to the understanding, prevention, and treatment of the epilepsies.

In contrast, **Seminars in Epileptology** are more educational and specifically address the competencies and learning objectives of the ILAE. This section provides a platform to publish a broad range of educational material.

The Genetic Literacy series

During the second half of 2017, the ILAE made the decision to move the Genetic Literacy series, launched by The ILAE Genetics Commission, from *Epilepsia* (Tan et al., 2015) to *Epileptic Disorders* (Myers et al., 2018) as part of the ILAE's reaffirmation of *Epileptic Disorders* as the ILAE's main educational journal. The overall aim was to provide a concise, accessible resource on epilepsy genetics for the busy, on-the-ground clinician so that he/she can apply that knowledge at point-of-care to help patients. A special effort was made by the respective Editors-in-Chief to ensure that the style and format of the series remains consistent.

Tan NC, Lowenstein DH; ILAE Genetics Commission.

Improving your genetic literacy in epilepsy-A new series.

Epilepsia 2015; 56(11): 1696-9.

Myers KA, Scheffer IE, Berkovic SF; ILAE Genetics

Commission. Genetic literacy series: Genetic epilepsy with febrile seizures plus. Epileptic Disord 2018; 20(4): 232-238.

Other recent review papers in this section include:

- The role of EEG in the diagnosis and classification of the epilepsy syndromes: A tool for clinical practice by the ILAE Neurophysiology Task Force (Part 1).
Koutroumanidis M, Arzimanoglou A, Caraballo R, et al. Epileptic Disord 2017; 19(3): 233-98.
- The role of EEG in the diagnosis and classification of the epilepsy syndromes: A tool for clinical practice by the ILAE Neurophysiology Task Force (Part 2).
Koutroumanidis M, Arzimanoglou A, Caraballo R, et al. Epileptic Disord 2017; 19(4): 385-437.

Epileptic Disorders (continued)

- A web-based diagnostic reference centre for the European Reference Network “EpiCare”: Recommendations of the eNeuropathology working group.
Kölble K, Cross JH, Becker A, Blümcke I. Epileptic Disord 2018; 20(5): 339-345.
- Roadmap for a competency-based educational curriculum in epileptology: Report of the Epilepsy Education Task Force of the International League Against Epilepsy.
Blumcke I, Arzimanoglou A, Beniczky S, et al. Epileptic Disord. In press.

The ongoing priority of the journal is to publish highly educational and informative material in line with the epilepsy curriculum defined by the ILAE.

Alexis Arzimanoglou
Co Editor-In-Chief

ILAE Wikipedia Epilepsy Project



Nicola Maggio

2018 was the kick-off year for the Wikipedia Epilepsy Project. Upon approval of the strategic plan by the ILAE Executive Committee, two Associate Editors were recruited (Dr. Selim Benabadis, MD – University of South Florida and Dr. Atul Maheshwari, MD – Baylor College of Medicine). The first three epilepsy-related Wikipedia entries edited by the ILAE team were written in collaboration with medical students at Tel Aviv University in Israel (TAU), under the supervision of Shani Evanstein Sigalov, an EdTech Innovation strategist at TAU who also heads the Wikipedia project, Medicine. Since the appearance of edited entries in Wikipedia, an average of 240 views/day have been collected. Under this collaboration, work is in progress for editing three additional entries.

A webpage on the ILAE website dedicated to the Wikipedia Epilepsy Project (<https://www.ilae.org/journals/ilae-wikipedia>) has also been established. Besides summarizing the work done by the team, this page also links to the edited epilepsy-related Wikipedia entries.

Novel collaborations which are expected to increase both the activity and the impact of the project were also established in 2018. Medical students at the University of California - San Francisco, under the supervision of Dr. Amin Azzam

(Clinical Professor of Psychiatry at UCSF and Wikipedian) are going to be recruited in order to increase the number of edited epilepsy-related Wikipedia entries written by non-professionals.

The YES community of the ILAE (Dr. Christos Lisgaras, PhD, and Neha Kaul) has also been recruited to write novel, previously unpublished epilepsy entries for Wikipedia in 2019. A collaboration with WikiEDU (the educational arm of Wikipedia) is also in progress. This collaboration is expected to develop a curriculum for a course aimed at teaching the Wikipedia environment to healthcare professionals in the field of epilepsy.

Finally, additional activities planned in 2018, which will take off in 2019 are: (1) recruiting a publishing associate editor; (2) engaging social media for the project; (3) run the first Wikipedia Edit-a-Thon event dedicated to the project at the 33rd International Epilepsy Congress in Bangkok, Thailand.

Nicola Maggio, MD, PhD
Chief Editor

Interactive Media

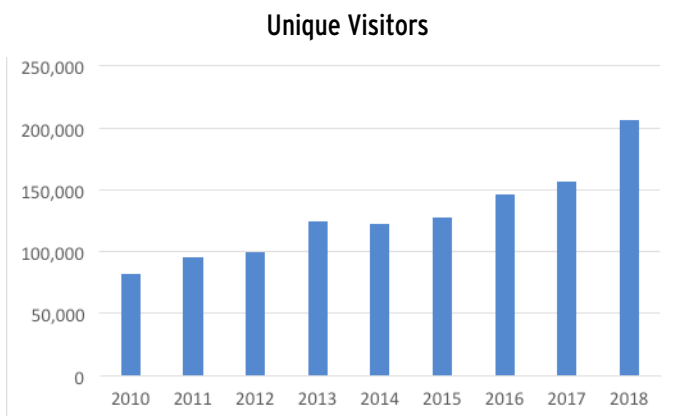
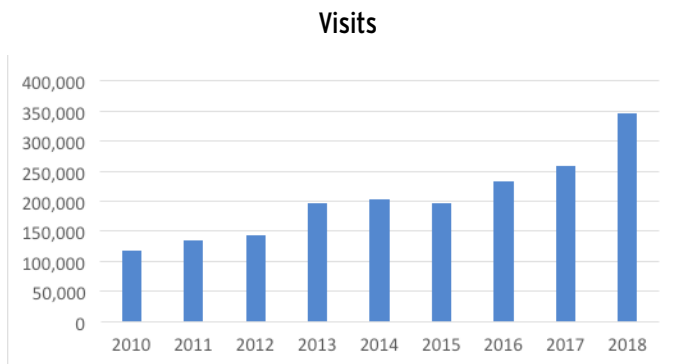


Jean Gotman

Please note that this report is quite similar to the 2017 report, which was written half-way through 2018, and reported on web activity for the first six months of 2018. This report is about the full 2018 year and the comparison to previous years.

In 2018, the first full year using the redesigned site, the web team continued to refine and explore the capabilities of the content management system.

While we can't show page-by-page comparisons with previous years due to the reorganization, the number of visits and unique visitors continued to climb overall, with **an increase of 33% in 2018**. We now have **three times more visitors than in 2010**. The most popular pages by far continue to be Definitions & Classification and Guidelines.

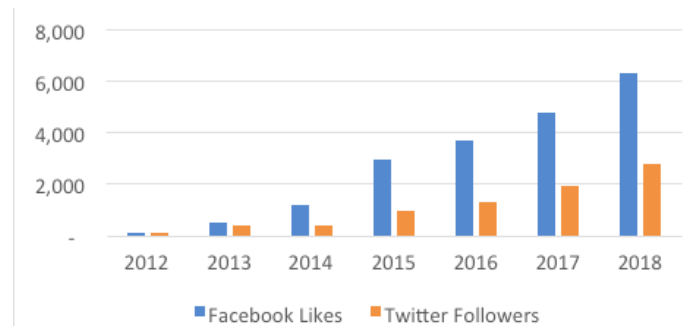


Devices

A primary reason for redesigning the site to use a content management system was to make the site more responsive and thus, readable for those using the smaller screens of mobile devices. This decision is validated by the increasing proportion of visits from mobile devices, which are now close to 30% of our total visits.

The graph below shows how the proportion of visits from mobile devices is increasing regularly. It is interesting to see the decline in the use of tablets, probably as a result of the availability of larger smartphones.

ILAE Social Media Impact



Multilingual content

Multilingual content has expanded, both on the website and in social media, in support of ILAE's global mission. The website now has content available in 21 different languages. Spanish is the most-used language, and visits from Spanish-speaking individuals soared to 60,764 in 2018, from 28,156 in 2017. Reflecting this, our Spanish content page is the sixth most-visited page on the website.

In terms of content, our Guidelines and Classification reports and documents are the most-translated; the Practical Clinical Definition of Epilepsy (2014) is now available in 11 languages other than English!

Interactive Media *(continued)*

Social media and the next generation

We continue to reach more people via our social media accounts. The graph below shows the year-over-year increase in both Facebook likes and Twitter followers. The increase in 2018 is also more marked than previous increases.

In 2018, working with the Young Epilepsy Section (YES), we began to regularly post to ILAE Twitter accounts in Spanish (@IlaeES), French (@ILAE_FR), Portuguese (@Ilae_PT), and Japanese (@ILAE_JP), in addition to YES (@yesILAE).

Newsletters

We continue to send a monthly electronic Newsletter, containing highlights of League activities and publications,

to a mailing list of over 10,000 email addresses (reduced from around 15,000 with the implementation of the GDPR (General Data Protection Regulation) in Europe.)

e-Newsletters are sent monthly, and when there are items of special importance. Emails are sent twice a month when new Epigraph articles are ready. The content of the newsletters is developed by the team, with input from the IDM office and from Wiley, to include items important to these groups, and to make sure that the most important ILAE issues receive broad distribution.

Submitted by Deb Flower, Jean Gotman and Priscilla Shisler

Our most popular tweet in 2018 contained "infographics" created by YES members for our guidelines.

Tweet	Impressions
Classification of Seizure Types Infographic	12,101
Large international study discovers 11 new epilepsy genes: Genome-wide mega-analysis identifies 16 loci ... ILAE Consortium on Complex Epilepsies	9,984
Cannabis-based products for pediatric epilepsy: A systematic review. Elliott, et al.	9,086

International Director of Meetings



Richard Holmes

In 2018, the Congress Team managed the 12th Asian & Oceanian Epilepsy Congress, the 13th European Congress on Epileptology, and the 10th Latin American Epilepsy Congress.

These congresses had a total of 4,550 attendees, 477 speakers and Chairs, 1,475 abstracts received and 91 bursaries awarded.



12th Asian & Oceanian Epilepsy Congress, Bali, Indonesia
28th June-1st July 2018

The organising committee, chaired by Byung-In Lee (South Korea), Parthasarthy Satishchandra (India) and Kurnia Kusumastuti (Indonesia), comprised eight members. The venue was the Prime Plaza Hotel, Sanur. There were 1,175 attendees and 52 countries were represented.

Congress programme:

- The programme comprised 42 sessions, with 107 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 were: 'Epilepsy surgery in patients with normal MRI', 'Infections of the nervous system and epilepsy', and 'Genetic investigations in epileptic encephalopathies'.
- The Chairman's Symposium: 'Personalised medicine in epilepsy'.
- The scientific programme had a wide range of Main, Post-Main and Parallel Sessions. The Masakazu Seino Memorial Lecture was entitled, 'Epilepsy care: Issues related to work, leisure, upbringing and culture'.
- 40 abstracts were selected for oral presentation in eight Platform Sessions.

- The Asian Epilepsy Academy (ASEPA) organised a teaching programme which included four ASEPA Workshops and five ASEPA Didactic Lectures, and, in addition, a Dietary Workshop was held at the end of the congress.
- The IBE Epilepsy and Society Symposium took place on the final day of the congress and was deemed a great success by all who participated in it.

Other highlights:

- Awards presented:
 - Asian Oceanian Outstanding Achievement Epilepsy Award – Simon Harvey (Australia), Zhen Hong (China), Shang-Yeong Kwan (Taiwan), Zarine Mogal (Pakistan).
 - The Golden Light Award – Katherine Height (Australia), Shuorong Huang (China), Ern-Chun Hung (Taiwan).
- 458 abstracts were received, and 29 bursaries were awarded.

13th European Congress on
Epileptology Vienna | August 26-30, 2018
ILAE | ILAE-CEA

13th European Congress on Epileptology, Vienna, Austria
26th-30th August 2018

The organising committee, chaired by Meir Bialer (Israel) and Eugen Trinko (Austria), comprised nine members. The venue was Messe Wien Congress Center. There were 2,650 attendees and 98 countries were represented.

Congress programme:

- The programme comprised 100 sessions, with 265 speakers and Chairs.
- The programme was created by the International Scientific and Organising Committee, incorporating proposals submitted by ILAE and IBE Chapters and commissions/

International Director of Meetings *(continued)*

committees, and experts in the field. Main session topics were: 'Acquired epilepsies: Mechanisms, therapeutic advances and unmet needs'; 'Advances in the development of diagnostic and prognostic biomarkers for childhood onset epilepsies'; 'Targeted therapy'; and 'Tauopathies and epilepsy'.

- The Chairs' Symposium: 'Recent advances and treatments in status epilepticus'.
- The scientific programme had a wide range of Main and Parallel Sessions, Teaching Sessions, a debate, ECE Forums and video sessions, and ended with a Highlights Session.

There were several special sessions, including: ILAE-CEA – EAN (European Academy of Neurology) Symposium, Symposium of Excellence in Epileptology, 'Cannabinoids going back and ahead', and the session reporting on The European Study on the Burden and Care of Epilepsy (ESBACE). There was also a Social Care Forum: Facilitating self-management in epilepsy and a Patienten-Forum: "Epilepsie – aktiv leben" – Anfälle erkennen, beraten und behandeln.

- 105 abstracts were selected for platform presentation in 18 sessions.

Other highlights:

- ILAE Mentor Programme: Second iteration (introduced at IEC 2017); 20 participants.
- ILAE Leadership Development Programme: Third iteration, but first at a regional congress (previously held at IEC 2015 and 2017); 27 participants.
- ILAE-YES activities: Exhibition stand; Fun Run; networking event; brainstorming meeting; ECE Forum
- Awards presented:
 - European Epileptology Award - Emilio Perucca (Italy)
 - European Epilepsy Education Award - Kristina Malmgren (Sweden)

- European Epilepsy Service Award - Finola Quinn (Ireland)
- Young Investigator Awards - Birgit Frauscher (Austria/ Canada) & Sylvain Rheims (France)
- 869 abstracts were received, and 39 bursaries were awarded.



10th Latin American Epilepsy Congress, San José, Costa Rica 29th September-2nd October 2018

The organising committee, chaired by Franz Chaves-Sell (Costa Rica), Marco T. Medina (Honduras) and Tomás Mesa Latorre (Chile), comprised eight members. The venue was the Real Intercontinental Hotel. There were 725 attendees and 33 countries were represented.

Congress programme:

- The programme comprised 30 sessions, with 105 speakers and Chairs.
- The programme was created by the Scientific and Organising Committee incorporating proposals submitted by ILAE and IBE Chapters and commissions/committees, and experts in the field.
- The scientific programme had a wide range of sessions and the specially-created Presidential Symposium entitled, 'The gap in epilepsy management in Latin America'.
- Four ALADE Courses; Four workshops on 'II Latin American Workshop on Neurobiology of Epilepsy', 'Law and Epilepsy', 'Epilepsy and Media' and 'Epilepsy Surgery Workshop I&II'.
- Eight abstracts were selected for platform presentation in two sessions.
- 148 abstracts were received and 23 bursaries were awarded, as well as 25 registrations provided to the Mexican Chapter of the ILAE.

International Director of Meetings *(continued)*

- IBE day: 15 educational sessions, 1st Latin American Meeting of Young People with Epilepsy.

Other highlights:

- ILAE-YES activities: Exhibition stand, networking event, brainstorming meeting.
- Awards presented:
 - Outstanding commitment to treat epilepsy in the Costa Rican Community - Oscar Mauricio Sittenfeld Appel.
 - Posthumous Recognition - Natalio Fejerman (1933-2018).

Future Congresses

The Congress Team is currently working on arrangements for the upcoming congresses in 2019 (**5th East**

Mediterranean Epilepsy Congress, Marrakech, Morocco; **33rd International Epilepsy Congress**, Bangkok, Thailand; **4th African Epilepsy Congress**, Kampala, Uganda; **1st European Epilepsy Forum**, Brussels, Belgium) and 2020 (**11th Latin American Epilepsy Congress**, Santiago de Chile, Chile; **14th European Congress on Epileptology**, Geneva Switzerland; **2nd North American Epilepsy Congress**, Toronto, Canada; **13th Asian & Oceanian Epilepsy Congress**, Fukuoka, Japan), as well as the international and regional congresses (**34th International Epilepsy Congress**, Paris, France; **6th East Mediterranean Epilepsy Congress**; **5th African Epilepsy Congress**) in 2021, and regional congresses in 2022.

Richard Holmes
International Director of Meetings

Headquarters and Chapter Services Staff



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



Deborah Flower supports the League in the position of Web Content Administrator and works closely with Jean Gotman to create, execute and maintain web content and functional enhancements. Deb maintains the membership and mailing databases reaches out regularly to Chapter and Regional contacts for photos and updates and coordinates the monthly eNewsletter, Epigraph and the Annual Report. Additionally, she provides administrative and web support to Commissions and task forces.



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.



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



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.

Communications Task Force



Ed Bertram

Chair

Edward Bertram (USA)

Members

Roberto Caraballo (Argentina)

Derrick Chan (Singapore)

Jean Gotman (Canada)

Alla Guekht (Russia)

Akio Ikeda (Japan)

Angelina Kakooza (Uganda)

Neha Kaul (Australia)

Mary Secco (Canada)

Chahnez Charfi Triki (Tunisia)

Eugen Trinka (Austria)

Samuel Wiebe (Canada)

The Communications Task Force was established with the goal of informing the epilepsy community, governments, and non-governmental organizations, as well as the broader public, about epilepsy. Topics will include the consequences of the disease on people's lives and how these consequences can be ameliorated through treatment, research and changes in laws. By informing about epilepsy, we will take the perspectives of the patient and family, clinicians, social workers, researchers and advocates. **Another goal is to educate our members about how their colleagues and the League are addressing the challenges related to epilepsy.**

Communications is the public face of the ILAE and its efforts. Effective communication is what lets members know that their organization is active on their behalf. The stories may also support resource development efforts. Avenues for publication include Epigraph, our website and the general media.

Organization

During the course of this effort, we will develop a number of working groups that will be closer to specific issues. The working groups will focus on the patient experience with epilepsy in many systems, the clinicians' perspective on the many issues that go unresolved and unaddressed, and the advocacy efforts to present epilepsy to the general

public. **Whenever possible, we will present how finding solutions improved people's lives.** An underlying message is that progress has been made and will continue to be made. Members of the working groups will be responsible for identifying topics and, in some cases, assist with the writing of articles or identifying authors for those articles.

It is important to provide the patient perspective in order to inform on the experience of patients and families affected by epilepsy internationally, with an emphasis on the barriers to having a normal life. The goals are to highlight the many challenges that are placed by medical systems and social prejudices, and also to present potential solutions to these challenges in the many different cultures of our community. This topic may also be viewed as an opportunity to lobby for patient needs and for creating standards of care.

We will also provide articles on the physician experience. All physicians encounter challenges while caring for their patients. Some challenges are systemic in the health care system and others are cultural. Many have found ways of overcoming these issues, but other barriers require a concerted effort by providers to create a remedy. It will be necessary to work with physicians from our regions to identify the key challenges and show how they can be solved. These efforts may provide examples to colleagues on how to find solutions to their situations.

Advocacy and external relations are also a major focus for the League. In order to create support for epilepsy care and research, there is a great need to present epilepsy in its current state to governments, NGOs and charitable institutions. We must promote epilepsy and the contributions our members are making to their home institutions. One goal is to develop compelling rationale about the need for greater support for epilepsy, both nationally and globally. The League will use its unique position as an outside party to promote epilepsy as a priority in health systems. This effort will also contribute to the case for resource development.

Communications is also a tool for professional and lay education. A final major goal is to educate our community

Communications Task Force *(continued)*

about advances in research that are being made, and to present new and promising therapies.

Inherent to all of our communications efforts is the creation of a Global Epilepsy Community. Although the specific needs vary greatly across our many chapters, there are also many common problems that have solutions that easily cross borders. We want to help our members learn from one another's experiences.

Because of the great need and scope for professional-level communications, we decided to employ our first Communications Officer. After an extensive search, we asked Nancy Volkens to begin the process of upgrading the quality and quantity of our feature articles at the beginning of May. Nancy has extensive experience in scientific and medical writing. One of our stated goals is to give epilepsy greater visibility outside the epilepsy community.

Shortly after our first *Epigraph* this summer, Nancy got us started with Newswise/Medwire, an online news awareness organization to which we are now a subscribing member. We have essentially unlimited access for a year to upload stories (text or video) to which subscribers around the world will have access. All of our *Epigraph* articles have been posted, and they have received a total of over 52,000 views (see table

below for views as of November 19, 2018). Not surprisingly, the cannabis debate has done well, but the PET course article and the article on CT's Seino lecture in Bali have also drawn a lot of interest. The news report on caffeine that Stacia Kalinoski created from the Vienna meeting has been seen by over 7,000 viewers (much more than when the story was placed on our YouTube channel).

Also, many of these articles have been placed on other websites, increasing our visibility. The articles on emergency department imaging and status epilepticus were picked up by the American Association of Neurological Surgeons and placed on their website. The most recent article on Alzheimer's and epilepsy had 3,500 views in five days, and was re-posted on ten other sites. Reaching out to a media distribution organization has been useful in getting epilepsy-related material out to a broader audience.

In these initial stages of our communications expansion, we are working to publicize a variety of topics drawn from our journals, our congresses and from suggestions by our members. As we continue to develop and expand our communications portfolio, we will look for more sources and begin establishing advisory boards to make suggestions and provide feedback. As true video news reports and audio podcasts are popular, we will also examine how we can add these media as well. Part of this effort will involve recruiting members to serve as field reporters.

Real Time Hits is a report of the total pageviews on your article. Each "hit" equals a click to view your article.

Lib	Date	Title	Total to Date
November 2018			
Med	13-Nov	Alzheimer's disease and epilepsy: Unraveling the Connections	3581
Med			
October 2018			
Med	24-Oct	Time is Brain: Treating Status Epilepticus	5472
Med	24-Oct	Epilepsy in the emergency department: Too much neuroimaging?	5431
Med	10-Oct	Does Caffeine Increase Risk for Seizures?	7411
Med	10-Oct	Neonatal seizures: Closing the knowledge and treatment gap	4335
Med	03-Oct	Overcoming the stigma of epilepsy in Asia: Cues from Confucius?	5821
September 2018			
Med	04-Sep	One-Day Pediatric Epilepsy Training Becomes Worldwide Movement	7193
Med	04-Sep	Proof of Concept Study Aims for Rapid Genotyping to Guide Epilepsy...	5886
August 2018			
Med	07-Aug	Meet the New Drug, Same as the Old Drug: Influx of New Epilepsy Medications...	3471
Med	07-Aug	Cannabis for Epilepsy? Debate Addresses Opinions on Medical Marijuana for...	4839

Communications Task Force *(continued)*

The *Epigraph* emails have driven new visits to the website, and the links in the emails are the primary path for finding the articles. What is also interesting is the length of time people stay on the page. These *Epigraph* articles have some of the longest visit times on the League site. These longer stays suggest that many are reading the articles in full. One of the primary hindrances to access is our recently severely reduced email list (the result of the GDPR), and we are actively working to correct this problem.

At present, we are planning two *Epigraph* issues monthly, but the number of suggested articles suggest that we have enough potential material for weekly editions.

One of the major issues we need to address is how to identify topics and themes. Our overall goal is to create articles that will inform and educate, and create a greater sense of community by introducing our members and their challenges and successes to one another. We also want to keep our members informed about the latest developments in advocacy and research in ways that are understandable to a broad constituency.

At present, the majority of our articles are being developed from content at meetings, as well as from reviews of our (and other) journals. This approach was taken because these two venues typically have material that lends itself to news features. However, many of our articles have, and will continue to, come from “person in the street” encounters.

In summary, the first six months of our expanded communications effort have seen a significant increase in articles and in our efforts to reach outside the core epilepsy community. In the coming year, we plan to increase the number of articles, broaden the topics covered and engage in new approaches, all to reach a broader public.

Edward Bertram
Chair

Epilepsy Education Task Force



Ingmar Blümcke



Wei-ping Liao

Co-Chairs

Ingmar Blümcke (Germany)

Wei-ping Liao (China)

Commission and Task Force Members

Raidah Al Baradie (Saudi Arabia)

Alexis Arzimanoglou (France)

Sandor Beniczky (Denmark)

Ed Bertram (USA)

Martin Brodie (UK)

Leonor Cabral-Lim (Philippines)

Jaime Carrizosa (Colombia)

Hannah Cock (UK)

Monika Eisermann (France)

Jean Gotman (Canada)

Martin Holtkamp (Germany)

Günter Krämer (Switzerland)

Cecilie Johannessen Landmark (Norway)

Shichuo Li (China)

Shih Hui Lim (Singapore)

Nicola Maggio (Israel)

Ivan Rektor (Czech Republic)

Christoph Schöne-Bake (Germany)

Jo Wilmshurst (South Africa)

Sarah Wilson (Australia)

Elza Marcia Yacubian (Brazil)

Eva Biesel (Germany)

Priscilla Shisler (USA)

MC Liaison

Sam Wiebe, Past Chair (Canada)

Goal

Teaching of competencies in diagnosis and clinical management of epilepsy is of utmost importance for the ILAE. Moving to an “outcomes” or “competency-based” approach for the organization of educational materials will allow for a more systematic and strategic approach to developing educational offerings. Furthermore, it will make it possible to create formal programs for a variety of learner levels, which can be undertaken in a step-wise, self-paced fashion at various levels. Epilepsy Education (EpiEd) will

develop tools to address this issue and pave the way towards a web-based, 21st century virtual campus and teaching academy.

Achievements

EpiEd developed a competency-based curriculum for epileptology covering the spectrum of skills and knowledge for best medical practices. The curriculum encompasses seven domains, 42 competencies and 124 learning objectives, divided into three levels: entry (Level 1), proficiency (Level 2) and advanced proficiency (Level 3). It will be available at the ILAE website and submitted for publication in the *Epileptic Disorders* journal.

Our survey of existing and ILAE endorsed teaching activities identified a significant gap in the education of basic knowledge of epileptology (Level 1). To bridge this gap, a web-based eLearning platform is being developed with the help of our new project manager, Eva Biesel. The first case-based and interactive pilot module has been developed in English, with the help of our YES member, Christoph Schoene-Bake, and was presented at the 2018 Annual Meeting in New Orleans.

Future Plans

In 2019, we are planning to implement more case-based eLearning modules for Level 1 to cover the spectrum of most common epilepsies. All courses will be managed by a new web-based Learning Management System, extensively tested by our constituency to assess needs and to guarantee successful implementation of our program. Another goal is to make courses available in other languages, i.e. Spanish, Chinese, and Russian, and adapting the content to the specific socio-economic background(s) of the target audience. We also plan to develop a virtual campus around the curriculum, integrating the various educational activities of the ILAE. Each teaching activity will be mapped to learning objectives as specified by the curriculum. Systematic implementation of post-course evaluation of achievements will be another milestone to be introduced into all ILAE-endorsed teaching activities in the near future.

Ingmar Blümcke, Co-Chair

Epilepsy Guidelines Task Force



Nathalie Jette



Francisco Brigo

Co-Chairs

Nathalie Jetté (USA)
Francisco Brigo (Italy)

Members

Sanjaya Shanthiputhra Fernando (Sri Lanka)
Jacqueline French (USA)
Lara Jehi (USA)
Martin Kirkpatrick (UK)
Eva Kumlien (Sweden)
Katia Lin (Brazil)

MC Liaison

Samuel Wiebe (Canada)

Aims of the Task Force

- (1) Develop a CPG development toolkit webinar
- (2) Create a webpage on the ILAE website for this task force, with links to existing epilepsy guidelines
- (3) Update the list of epilepsy guidelines annually and upload them to the website
- (4) Test the CPG development toolkit
- (5) Develop implementation guidance for low/middle and high-income countries
- (6) Develop an educational paper on “what is a guideline”

Commission activities

This group had several conference calls to discuss the ongoing tasks of this group. Main activities have included:

- + Ongoing update of the systematic review of epilepsy guidelines
- + Creation of a podcast on guideline development
- + The creation of a list of attributes that are used to classify all 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 the data of number of guidelines excluded in prior systematic review on guidelines attached and how many were from high vs. low impact journals, etc.) - perhaps
- 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
- What to do when the evidence is poor (e.g. consensus methodology, etc.)
- What people should 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 the applicability of guidelines
- When 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. We will continue to update our ILAE guideline development toolkit, and provide methodological expertise to ILAE committee and members who are working on developing guidelines. A new working group will be created and will develop guidance on guideline implementation strategies and how to adapt existing guidelines in low- and middle-income countries.

Nathalie Jetté
Co-Chair

ILAE Driving Task Force



Alejandro de Marinis



Nathalie Jette

Chair

Nathalie Jetté (USA)
Alejandro de Marinis, Co-Chair

ILAE Driving Task Force Core Advisory Group

Amza Ali (Jamaica), Secretary
Ettore Beghi (Italy)
Mary Secco (Canada), IBE
Michael Sperling (USA)
Anthony Zimba (Zambia), IBE

ILAE Driving Task Force Members (Original Group)

Amza Ali (Jamaica), Secretary
Ettore Beghi (Italy)
Tarun Dua (Switzerland), WHO
Alla Guekht (Russia)
Seung Bong Hong (Korea)
Colin Josephson (Korea)
Makiko Osawa (Japan)
Michael Sperling (USA)
Eugen Trinkla (Austria)
Manjari Tripathi (India)
Yuping Wang (China)
Anthony Zimba (Zambia), IBE

MC Liaison

Samuel Wiebe (Canada)

The Driving Task Force (DTF) came into existence on September 3, 2017, with its first meeting convened in Barcelona during the 32nd International Epilepsy Congress. Since then, a core committee of this Task Force (TF) was also created to help coordinate and facilitate its work.

The first step was to define the TF Mission and Vision as follows:

“The main objective (Mission) of this Task Force is to develop recommendations that will support worldwide

efforts to facilitate the implementation of fair and equitable driving regulations for people with epilepsy (PWE). The goal (Vision) is that these standards should improve the quality of life of PWE, by providing them with reasonable access to a driver’s license, when appropriate, based on an adequate risk assessment.

Task Force deliverables were discussed, and an initial set of deliverables formulated. These were discussed during the following months, including an initial conference call held in November 2017. During this conference call, Dr. Amza Ali agreed to be the Task Force Secretary. It proved difficult to set up conference calls that included the majority of participants, thus resulting in delays in achieving the group’s aims. Thus, a smaller Core Group was created to assist in setting priorities for the overall group.

The latest TF deliverables include:

- a. Systematic review of driving outcomes associated with epilepsy
- i. Manuscript will be prepared for *Epilepsia*
- b. Risk assessment compared to other groups
- i. Manuscript will be prepared for *Epilepsia*
- c. Inventory of driving standards
- i. A report will be published for the ILAE website
- d. Define gaps in the area of driving research, policy, etc.
- e. Develop standards and recommendations about driving with epilepsy based on the above work
- i. Manuscript will be prepared for *Epilepsia* incorporating findings from deliverables ‘d’ and ‘e’.

Nathalie Jetté
Co-Chair, Driving Sub Task Force

Global Outreach Task Force



Shichuo Li



Mary Secco

Chair

Shichuo Li (China)
Mary Secco (Canada)

Members

Alla Guekht (Russia), Past Chair
Fatema Abdullah (Bahrain)
Martin Brodie (UK), IBE President
Leonor Cabral Lim (Philippines)
Lilian Cuadra Olmos (Chile)
Tarun Dua (Switzerland), WHO
Gardiner Lapham (USA)
Abdullahi Ibrahim (Nigeria)
Seinn Mya Mya Aye (Myanmar)
Emilio Perucca (Italy)
Pravina Shah (India)
Sam Wiebe (Canada), ILAE President
Jacob Mugumbate (Zimbabwe)

Global Epilepsy Report and Global Epilepsy Survey

Our Global Outreach Task Force (GOTF) has been working with the WHO for the past year to write a Global Epilepsy Report. The goal of this report is to raise awareness of epilepsy as a public health priority, to facilitate member states' political commitment towards epilepsy, to highlight the global burden of epilepsy, to articulate a public health approach, and to advocate for actions at the national and international levels to address the epilepsy knowledge and treatment gap.

The report will include:

- ✦ An Executive Summary
- ✦ The global burden of epilepsy
- ✦ Leadership, governance, policy, plans and programs for epilepsy
- ✦ Health care response
- ✦ Access to anti-seizure medications

- ✦ Stigma and misconceptions – the social response
- ✦ Prevention of epilepsy
- ✦ Research on epilepsy
- ✦ Way Forward

To date, over 40 individuals representing the ILAE, IBE, and WHO have been actively engaged in writing this report. Our plan is to launch and disseminate this exciting report in partnership with the WHO in June 2019 at the 33rd International Epilepsy Congress (IEC) in Bangkok. World Health Assembly May 2018 Members of the GOTF attended the 71st World Health Assembly in Geneva in May 2018. Our objective was to meet with policy makers from member states around the world to highlight the epilepsy treatment and knowledge gap. In Geneva, our first advocacy event was on May 22, where we co-hosted a two-hour lunch and panel with the theme, Calling to Global Action for Epilepsy. Approximately 80 attendees (World Health Organization staff, policy makers, NGO's, delegates from member states, UCB and other industry sponsors) attended the event. After lunch, our panel spoke about the burden of epilepsy on the family, the community and the healthcare system. Our unified message was to ask policy makers and the WHO to make epilepsy a public health priority with a sustained commitment towards implementation of the Epilepsy Resolution WHA 68.20.

On Friday, May 25 in the late afternoon at the 71st World Health Assembly, we were invited to make formal statements related to the progress of implementing Epilepsy Resolution WHA 68.20. Both the ILAE and IBE stated that progress has been slow and that we needed a sustained effort and an 'Epilepsy Global Plan of Action'. There were written and oral statements from the World Federation of Neurology, the IBE and the ILAE.

The first country to speak on behalf of the Resolution was Russia. Russia had three core requests for the 194 member states:

Global Outreach Task Force *(continued)*

1. A new report on the implementation of Resolution WHA 68.20 to be prepared and discussed at the 74th WHA in 2021;
2. Development of an 'Epilepsy Global Plan of Action';
3. An item on epilepsy be included in the 144 Executive Board agenda in January 2019.

Ministry of Health officials from Honduras, Zimbabwe, and China also spoke in support and identified that we need to extend the reporting period on the Resolution, as the work has not been completed. To achieve the three goals, we will

require a collective response from ILAE and IBE chapters. Our task force has been working to mobilize action at the country level. Specifically, we have been liaising with ILAE and IBE chapters, encouraging them to engage with policy makers for inclusion of the epilepsy item into the agenda of the 144 WHO Executive board. The executive board meeting began on January 24, 2019.

Mary Secco
Co-Chair, Global Outreach Task Force

Joint IFCN-ILAE Task Force on EEG Databases



Sándor Beniczky

Chair:

Sándor Beniczky (Denmark)

Members:

ILAE:

Jean Gotman (Canada), EC Liaison

Ingmar Blümcke (Germany)

Don Schomer (USA)

William Tatum (USA)

Sam Wiebe (Canada)

Elza Marcia Yacubian (Brazil)

IFCN:

Aatif Husain (USA), EC Liaison

Luis Caboclo (Brazil)

Nick Kane (UK)

Akio Ikeda (Japan)

Marcus Ng (Canada)

Paolo Rossini (Italy)

Michel van Putten (Netherlands)

Pedro Valdes Sosa (Cuba), OHBM Liaison

Christoph Michel (Switzerland), OHBM Liaison

Executive summary

The taskforce recommends:

1. Bridging Solution: Until the more elaborate educational and clinical research database (see below) is developed, the task force recommends a bridging solution that can be made operational in the second half of 2018. This intermediate solution will address the educational goals of IFCN and ILAE.

2. Educational and clinical research database: A more elaborate solution will be developed, addressing the specific needs. The taskforce suggests that Stefan Rampp, Persyst and Holberg EEG collaborate on this project. Stefan Rampp will coordinate, as project manager, the web-based platform that integrates SCORE and the universal web-based EEG reader, from Persyst.

3. BIDS (Brain Imaging Data Structure) database: To be used as a platform for research projects in the domain of cognitive and translational neuroscience. BIDS is a flexible tool that can accommodate the huge diversity of these projects.

Taskforce Objectives

IFCN and ILAE have joined forces to develop an online interactive EEG database. The goal of the database will be to promote education and research (i.e. research using the data stored in the database). The database will comprise: (1) Raw-data: de-identified EEG and video-EEG recordings; (2) Annotations - features extracted and stored using the SCORE system (which was developed as part of an ILAE-IFCN collaboration); (3) Distinct graphical user interfaces (GUI) will be developed for the two main functions, which are education (open access) and research (limited to approved users). It is an additional goal and an advantage to link the EEG database to neuroimaging and clinical databases.

The educational part supports both self-study and integration with existing online and face-to-face courses.

The starting point was the web-based, interactive educational database using the SCORE system, which has been developed for the latest edition of the Niedermeyer EEG textbook. This includes 170 representative EEG/video-EEG samples, and will constitute a starting point for the future IFCN-ILAE database.

The database will have three components that need to be integrated: (1) the web-based platform for education and research; (2) the web-based universal EEG reader; and (3) the system for standardized annotation of EEG and for storing these features (SCORE).

The objective of the task force was to analyze the possible solutions and make recommendations on how to develop the EEG database.

Joint IFCN-ILAE Task Force on EEG Databases *(continued)*

The selection process

Following the first meeting of the task force on December 3, 2017 (Washington, DC), an open call was sent to representatives of companies and to researchers who had previously developed web-based universal EEG readers and interactive educational databases. Prior to the meeting, the task force reviewed the documents sent by the potential providers of the technology. The detailed documentation of this process can be downloaded from the following link: https://drive.google.com/open?id=1IpTvTY3Xvyf5asbH46bre_v3Dr0-cDZe. At the second meeting of the taskforce, May 6, 2018 (Washington, DC), the following potential providers presented their proposals:

1. Harald Aurlen (Holberg EEG) demonstrated the interactive educational database, using the SCORE system that had been developed for the Niedermeyer textbook.
2. Nicolas Nierenberg (Persyst) presented the web-based universal EEG reader.
3. Stefan Rampp (Erlangen University Hospital) presented the web-based educational platform.
4. Cyril Pernet presented BIDS (BRAIN IMAGING DATA STRUCTURE: A simple and intuitive way to organize and describe neuroimaging and behavioral data)
5. Jonathan Halford was not able to attend the task force meeting. Therefore, Jean Gotman and Sándor Beniczky had met with him separately. Jonathan Halford told them that he did not have the necessary resources to develop the web-based educational and research database. The possibility of financing a graduate student, who would work on this during the next 3-4 years, was discussed, but there were a great many uncertainties to the plan. It was therefore concluded that this option would not be pursued.

The SWOT analysis of these proposals is in Appendix-1. Based on this data, the task force makes the following recommendations:

Bridging solution:

Until the more elaborate database (see below) is developed, the taskforce recommends a “bridging solution” that addresses the educational needs. This is an intermediate solution between the currently existing interactive, web-based educational tool that was developed for the Niedermeyer EEG textbook, and the more elaborate database described below. The students annotate and score EEGs, using the standardized system (SCORE) and then they compare their scorings with the expert scorings.

The bridging solution is provided by Holberg-EEG in collaboration with Persyst. The details, including timeline and costs, are summarized in Appendix-2. The estimated cost of developing this solution is 27,800 Euro. The estimated yearly costs for maintenance and support are 7,432 Euro and 109 Euro/active-user (depending on the total number of active users – for details see Appendix-2).

Besides these technical features, there is a need for consensus-based scorings of the samples (at present, the samples are scored by one expert). The members of the task force volunteered to score 20-30 samples each. The task force recommends that this solution is made available within the next 6-12 months.

Educational and clinical research database:

This is a more elaborate version of the bridging solution that will decrease the yearly costs and will make possible clinical research functionality such as uploading new data and using the stored data for clinical research. The task force recommends that Stefan Rampp, Persyst and Holberg EEG collaborate on developing the IFCN-ILAE educational and research database. Stefan Rampp will coordinate, as project manager, the development of the web-based platform that integrates SCORE and the universal web-based EEG reader from Persyst. Stefan Rampp has already started a dialogue with Holberg-EEG and Persyst, and will elaborate a detailed proposal on: (1) the architecture of the database; (2) the specific tasks/deliverables of the three collaborators; and (3) the timeline and the costs related to each task/deliverable.

Joint IFCN-ILAE Task Force on EEG Databases *(continued)*

Usage scenarios are detailed in Appendix-3. The terms of collaboration between the societies and the companies (Holberg-EEG and Persyst) need to be clarified, especially the aspect of the publicity that is intrinsic in developing the database using technical solutions provided by these companies. The task force will follow-up on these deliverables via email correspondence.

BIDS (Brain Imaging Data Structure)

BIDS is an ideal platform for collaborative research and for sharing EEG and neuroimaging data. Appendix-4 summarizes the essential features of BIDS. The task force recommends that IFCN and ILAE endorse it as the platform for cognitive/computational neuroscience projects and for

translational research. Aristeia Galanopoulou, Chair of the ILAE Commission on Neurobiology, has already been in contact with Cyril Pernet and discussed the possibility of using BIDS for EEG atlas for translational research. The task force recommends that the two societies promote use of BIDS – for example, by links to BIDS from their homepages, and possibly by inviting a paper on BIDS to be published in one of the societies' scientific journals. BIDS is an open and low-budget solution, requiring no/minimal funding.

Sándor Beniczky
Chair, Joint IFCN-ILAE Task Force on EEG Database

Next Generation Task Force



Helen Cross



Maeike Zijlmans

Co-Chairs

J. Helen Cross (UK)
Maeike Zijlmans (Netherlands)

Members

Marian Galovik (UK), Chair, Young Epilepsy Section
Sheryl Haut (USA)
Premysl Jiruska (Czech Republic)
Christos Lisgaras (Greece)
Rosa Michaelis (Germany)
Genevieve Rayner (Australia)

General

The Next Generation Task Force (NGTF) aligns activities from the ILAE leadership program (led by S. Haut), the ILAE mentor-mentee program (led by H. Cross), the Young Epilepsy section (led by M. Galovic), the young neurobiologist section (led by P. Jiruska), and any other committee or activity aiming at the younger generation of people involved in epilepsy care and research. The activities of the above-named sections are complementary to each other: The leadership program aims to involve next-generation leaders (around 35-45 years), the mentor-mentee program aims to involve young researchers (PhDs) and clinical fellows (30-40), and the young epilepsy section aims to attract people early in their career (20-40). The leadership program consists of talks by speakers from the epilepsy field on typical leadership topics like strategy, setting up groups, and budget planning. The feedback on the 2018 program in Vienna was very positive. The mentor-mentee program matches established clinicians and researchers with PhDs and fellows. While the feedback on the 2018 program in Vienna was positive, it included the suggestion to avoid overlap with other parts of the (YES) program. In the future, we intend that the contact between mentors and mentees remains during the year and this will be communicated in advance for the next program. The YES had a very active and productive year, as described below.

ILAE Young Epilepsy Section (YES)

The Next Generation Task Force identified the need to deepen the involvement of early-career researchers and clinicians within the ILAE, and to increase their participation at conferences. To achieve this, the idea of a grassroots-style organisation of young epileptologists and epilepsy researchers was born. We supported the development of the terms of reference for such an organisation and helped with the setup of the internal framework. We established a link with the ILAE Executive and the Young Epilepsy Section was formally recognised as the representative of young ILAE members.

We supported the first official YES meeting at a Kick-Off Workshop in London, UK, in May 2018. A diverse group of young people attended this event. The first YES General Assembly meeting was staged and YES representatives were elected. YES has since rapidly grown into a global initiative with several hundred active contributors from different backgrounds.

We facilitated the collaboration of, and ongoing exchanges between, YES and other ILAE task forces. Several ILAE task forces embraced the grassroots-style concept of YES and invited their members to successfully collaborate on projects. Particularly fruitful collaborations were established in the areas of education (cooperation on epilepsy curriculum development and cases), communication (support of social media accounts and creation of infographics), and conferences (networking events and career-development activities). Details of YES activities may be found in the separate Young Epilepsy Section report, found on page 86.

J. Helen Cross and Maeike Zijlmans
Co-Chairs, Next Generation Task Force

Nosology and Definitions Task Force



Paolo Tinuper



Elaine Wirrel

Co-Chairs:

Paolo Tinuper (Italy)
Elaine Wirrel (USA)

Members:

Edouard Hirsch (France)
Rima Nababout (France)
Nicola Specchio (Italy), Chair, childhood
syndrome subgroup
Eugen Trinka (Austria), Chair, Status Epilepticus
Sub Task Force
Sameer Zuberi (United Kingdom), Past Chair; Co-Chair,
Instruction Manual Sub-Task Force

Management Committee Liaison:

Samuel Wiebe

The Nosology and Definitions Task Force has been charged with two major goals:

1. To propose a list of epilepsy syndromes with clear definitions
2. To propose definitions and nosology for status epilepticus

Syndrome Definitions:

Four subgroups, based on typical age at presentation, have been defined: (1) Neonatal Syndromes, (2) Infantile Syndromes, (3) Childhood Syndromes, and (4) Adolescent, Adult, and Variable Age Syndromes. Our group held a productive meeting in Vienna, where we discussed whether specific surgical epilepsy entities (some of which were referred to as constellations in the 2010 report), or specific

gene epilepsies should also be defined as syndromes. If a surgical entity meets the definition of a syndrome (*a characteristic cluster of clinical and laboratory features in an individual with epilepsy, often with etiologic, prognostic, and treatment implications, possibly with age-dependent presentations and specific co-morbidities*), it can be considered a syndrome.

Small groups continue their work predominantly by teleconference to finalize syndrome definitions, building on the work already done on EpilepsyDiagnosis.org. For each proposed syndrome, we will provide a brief overview, clinical features (age at onset, sex ratio, antecedent history, development and cognition, neurological exam findings, natural history), seizure types (mandatory, possible, exclusionary), EEG features (interictal and ictal), neuroimaging findings, genetic associations, and important differential diagnoses. Our goal is to complete proposals for all syndromes in the next year, and then forward these to recognized international experts for their feedback.

Status Epilepticus:

The Status Epilepticus sub task force has finalized definitions for Refractory Status Epilepticus, Super-Refractory Status Epilepticus, New-Onset Refractory Status Epilepticus and Febrile-Infection Related Epilepsy Syndrome.

Paolo Tinuper, Eugen Trinka, Elaine Wirrell
on behalf of the Nosology and Definitions Task Force

Task Force on Traumatic Brain Injury and Antiepileptogenesis



Solomon Moshé

Chair

Solomon (Nico) Moshé (USA)

Members

Allen W Brown (USA)
Pablo Casillas (Australia)
Yunh-Hsiao Chiang (Taiwan)
Susan H Connors (USA)
Ramon Diaz-Arrastia (USA)
Pete Engel (USA)
Anthony Figaji (South Africa)
Alon Friedman (Canada)
Ali Gorji (Iran, Germany)
Damir Janigro (USA)
Michael Lipton (USA)
Laura Lubbers (USA)
Andrey Mazarati (USA)
Anthony Pacifico (USA)
Asla Pitkanen (Finland)
Mary Secco (Canada)
Paul Vespa (USA)
Vicky Whittemore (USA)
Aristea Galanopoulou (USA), Liaison

Neurobiology Commission

Nathalie Jetté (Canada), Liaison ILAE-North America

Management Committee Liaisons

Ed Bertram (USA)
Alla Guekht (Russia)

This is an update on the progress made by the ILAE Task Force (TF) on Traumatic Brain Injury (TBI) and Antiepileptogenesis during 2018. The list of deliverables includes:

1. Studying the development of epilepsy following TBI of various severities and etiologies, considering progress in translational studies, regional differences in the healthcare delivery, as well as input from the public. This includes bringing to the table key stakeholders to take advantage of the collective data and efforts.

2. Developing research priorities that promote coordinated research on this topic.

The task force members communicated by email, and the members who were attending the 2018 AES meeting participated in a face-to-face discussion on December 2, 2018. A survey of the members indicated the topics that the TF should pursue. These are:

A. Clinical Studies

- a. Current prospective population-based epidemiological analyses of post-traumatic epilepsy.
- b. Identify the injury mechanism resulting in post-traumatic epilepsy, and the relative prevalence of each in unbiased cohorts of TBI patients.
- c. Necessity of identifying and obtaining agreement on 'biomarkers' of epileptogenicity and epileptogenesis in TBI and PTE.
- d. Creation of large databases for best utilization, mining and evaluation of clinical data.

B. Preclinical Studies

- a. Development and validation of animal models of TBI that lead to post-traumatic epilepsy.
- b. Creation of large databases for best utilization, mining and evaluation of preclinical data.

A. Clinical Studies

From the clinical perspective, the focus is on collecting a large number of patients in the acute TBI setting, with similar extents of injury, or grouped into injury categories that make sense functionally (if possible). The TBI can affect many brain areas that may influence the development of epilepsy, as well as associated comorbidities. Additional information will be needed to sort out the effects of multisystem injuries and other factors such as the state of the gut microbiome.

Steps:

- Creation of a widely accepted severity scale based on clinical features, EEG, imaging, and fluid based factors at the earliest evaluation and regular intervals thereafter.

Task Force on Traumatic Brain Injury and Antiepileptogenesis *(continued)*

- Creation of a database where this information will be deposited is a key aspect, with information technology to include web-based and telemedicine components of recruitment, interventions and connections with individual participants, their families/significant others, and primary providers with the researchers, to guarantee as much retention as possible in future intervention studies.

There are currently several studies with databases, such as Federal Interagency Traumatic Brain Injury Research (FITBIR), the Epilepsy Bioinformatics Study for Antiepileptogenic Therapy (EpiBioS4Rx), TRACK-TBI, CENTER-TBI, TBI Model Systems National Database, Cure-DOD projects (TBI and Epilepsy databases), BOOST-3 (Brain Oxygen Optimization in Severe TBI—Phase 3), the Australia-New Zealand Critical Care Medicine Trials Network, and the Chronic Effects of Neurotrauma Consortium (CENC). The TF is discussing with the various PIs of these databases possible approaches to create common platforms. The goal is shared by the Epilepsy Research Program, the Congressionally Directed Medical Research Programs (CDMRP), NINDS, and the Cure Foundation, which at this point fund several TBI and Antiepileptogenesis projects.

B. Preclinical Studies

The development of animal models can occur in parallel, harmonizing data from various animal models and correlating to the human perspective.

Steps:

- Harmonization with the human data.
- Identification of additional models, including large animals, for better modelling of human TBI.
- Creation of collaborative environments for drug screening and treatments.

To accomplish these goals, members of the TF have created a clinical and a preclinical group. In addition, efforts are made to engage junior investigators in these research initiatives.

We are very pleased that our efforts have been accepted by the community. An example of this acceptance is seen in a communication by the Epilepsy Research Program (ERP) with the Congressionally Directed Medical Research Programs (CDMRP).

The ERP also coordinates its activities with the international epilepsy research community. The International League Against Epilepsy recently formed the Antiepileptogenesis Following TBI Task Force, with the goal of moving this topic forward from an international perspective. The task force will identify clear goals and steps that can be used to advance PTE science.

We would like to thank the ILAE for all of its support.

Dr. Solomon L. Moshé

Chair of the TBI Task Force on behalf of its members.

Publications Task Force



Jean Gotman

Chair

Jean Gotman (Canada)

Members

Alexis Arzimanoglou (France)
Sándor Beniczky (Denmark)
Edward Bertram (USA)
Aristea Galanopoulou (USA)
Günter Krämer (Switzerland)
Nicola Maggio (Israel)
Astrid Nehlig (France)
Priscilla Shisler (USA)
Michael Sperling (USA)
Dong Zhou (China)

MC Liaison

Emilio Perucca (Italy)

The main activity of the Publications Task Force (TF) is to oversee and coordinate the publications of the ILAE, to discuss general issues related to publications, and to propose solutions to existing problems, as well as extensions to current activities which could benefit ILAE.

The TF met in Hoboken, NJ in June and at the AES meeting in New Orleans, LA in December; each time for meetings lasting two-to-three hours. The budget of the TF is minimal, including refreshments for the meetings and \$10,000 to help with translating the ILAE documents (see below).

ILAE Journals

The TF heard reports from the three journals of the ILAE: *Epilepsia*, *Epilepsia Open*, and *Epileptic Disorders*. The journals are generally doing well. *Epilepsia Open*, the youngest journal, is growing well and it is expected that it should receive a reasonable impact factor (its first) in 2019. *Epilepsia* has maintained an IF above 5 and the IF of *Epileptic Disorders* has increased to 1.9. The coordination between the three journals has improved, with the flow of articles between the editorial offices now being satisfactory. The educational nature of *Epileptic Disorders* is now clearly entrenched. There were changes in the editors, with *Epilepsia Open* now having

A. Galanopoulou and D. Zhou as its Editors in Chief and *Epileptic Disorders* now having A. Arzimanoglou and S. Beniczky as its Editors in Chief.

The TF decided that all ILAE reports published in one of the three ILAE journals should include a two-page executive summary, which will be published in *Epilepsia*. This will facilitate the dissemination and translation of key ILAE documents.

The TF has recommended that all journal prizes be determined by the end of January. The Management Committee will then determine at which congress (international or regional) the prizes and accompanying lectures will be delivered.

The TF discussed the need to have a statistical consultant to verify the quality of some of the statistical analyses proposed in submitted articles. The issue will be discussed between the editors of *Epilepsia* and Wiley.

ILAE Wikipedia Project

The TF has worked actively with the Editor-in-Chief of the ILAE Wikipedia Project to ensure that the project team is able to write and edit as many Wikipedia entries as possible. Progress has not been as rapid as expected, as we became aware that editing Wikipedia entries is actually a very complex process, but cooperation has been sought from the ILAE Young Epilepsy Section (YES group), and young epileptologists are now being trained on how to edit Wikipedia entries. A three-hour Wikipedia editing workshop will take place at the 2019 International Epilepsy Congress in Bangkok.

Translation of ILAE documents

A substantial effort is being made by the TF to have key ILAE documents translated into as many languages as possible, to ensure broader accessibility and greater utilisation in clinical practice. An alternative, simplified translation procedure was put in place, in addition to the strict translation procedures which had been the ILAE policy

Publications Task Force *(continued)*

in the past. This has greatly facilitated the translation process. The three recent key documents of the ILAE (Definition of Epilepsy 2016, Classification of Seizures 2017, and Classification of Epilepsies 2017) have now been translated in ten, 11, and seven languages respectively. Financial support was provided by the TF to those who requested it (up to \$600 per document).

General issues

The TF is concerned with the possible impact that new initiatives regarding open access publishing (in particular, the European Plan S) will have on its journals, and the

revenue it draws from them for its operations. This issue was discussed but it remains very uncertain at this point as to how much these initiatives will impact publications. The ILAE presented a memo to the Plan S, which was made open for comment early in 2019.

Jean Gotman
Chair, Publications Task Force



Angelina Kakooza-Mwesige

Chair

Angelina Kakooza-Mwesige (Uganda)

Commission Members

Gallo Diop (Senegal), Past Chair

Mesu'a-Kabwa Luabeya (Democratic Republic of Congo),
Treasurer

Victor Sini (Cameroon), Secretary General

Jo Wilmsurst (South Africa)

Emmanuel Olatunde Sanya (Nigeria)

Edward Kija (Tanzania)

Ndeye Fatou Ndoeye (Cameroon)

Executive Committee Liaison

J. Helen Cross (UK)

ILAE Chapters in Africa

Benin

Cote d'Ivoire

Cameroon

Democratic Republic of Congo

Ghana

Guinea

Kenya

Mali

Nigeria

Rwanda

Senegal

South Africa

Tanzania

Uganda

Zimbabwe

ILAE-Africa Goals for the Term 2017-2021

1. Promote epilepsy awareness.
2. Improv access to epilepsy care.
3. Conduct training in epilepsy and strengthen the educational activities of ILAE-Africa.
4. Foster epilepsy research in the region.
5. Multiply ILAE membership in the region.

Task Forces for ILAE Africa

1. Raising Epilepsy Awareness

Angelina Kakooza M (Uganda)

Richard Idro (Uganda)

Augustina Charway-Felli (Ghana)

2. Education/Training Expansion

Jo Wilmshurst (South Africa)

Ansuya Naidoo (South Africa)

Charles Hammond (Ghana)

Pierre Luabeya (DRC)

3. Seeking Extra Funding Through Collaborations with Other Funders

Pierre Mesu'a-Kabwa Luabeya (DRC)

Desire Tshala (USA/DRC)

Athanase Millogo (Burkina Faso)

4. Increasing ILAE Membership

Edward Kija (Tanzania)

Victor Sini (Cameroon)

Dr Mecky (Sudan)

Birinus Adekaibe (Nigeria)

5. Communication/Foster Research Agenda

Emmanuel Sanya (Nigeria)

Birinus Adekaibe (Nigeria)

Lukman Owolabi (Nigeria)

Ndeye Fatou (Senegal)

6. Improving Access to Care

Ndeye Fatou Ndoeye (Senegal)

Athanase Millogo (Burkina Faso)

Achievements of ILAE-Africa in past term (2018)

1. Conducting of PET Courses

- Establishment of a 35-member faculty from 12 countries within Africa, to conduct Paediatric Epilepsy Training (PET) courses in collaboration with the British Paediatric Neurology Association in the UK.

ILAE-Africa *(continued)*

- So far, various courses have been held in Kenya, South Africa, Tanzania, Ghana, and Uganda and over 300 health professionals have been trained in paediatric epilepsy. Other courses are planned in 2019 for Uganda, Zambia, Zimbabwe, Ghana and Kenya.
- 2. A version of the CAA e-Newsletter `Epilepsy News Africa 2018` was published.
- 3. In conjunction with local partners, namely the Uganda Medical Association (U.M.A.) and the Uganda Pediatric Association (UPA), the local ILAE Uganda chapter conducted a sensitization symposium on `Epilepsy in Children` in September 2018 at the Rock Classic Hotel, in Tororo, a rural town in Uganda.

Symposium objectives:

- a. To raise public awareness about epilepsy, so as to create an atmosphere conducive for prevention, early

detection/diagnosis, effective treatment, and reduction of stigmatization and discrimination of people with epilepsy.

- b. To update and improve the knowledge and skills regarding epilepsy management among health professionals.
- c. To develop and/or improve strategies for advocacy, better prevention of, and care for people with epilepsy in the region.

This was achieved through varied scientific presentations related to updates on epilepsy care and management made by experts in the field. In addition, local FM radio talk shows for the public were conducted in English and the prevalent local languages of the area. A regional forum for people with epilepsy and their care givers, health professionals, teachers, and administrators was established to help address the needs and challenges posed by epilepsy in the region and beyond.



Symposium on Epilepsy in Children held in Tororo, Uganda, September 2018.

Challenges to epilepsy care in the ILAE-Africa region

1. Highest incidence and prevalence of active epilepsy compared to that of all other continents.
2. High levels of stigma and low community awareness of epilepsy.
3. Lack of basic infrastructure for adequate management.
4. Large epilepsy treatment gap, estimated at over 80%.
5. Lack of established standardized treatment guidelines for epilepsy and weak referral systems.
6. Limited human resources trained to take care of people with epilepsy (PWE).
7. Poor linkage between governments, regional and national epilepsy associations, and funding agencies in supporting epilepsy work.

Planned activities for the ILAE-Africa region in 2019

1. Conduct the 4th African Epilepsy Congress (AEC) in Kampala, Uganda, August 2019.
2. Conduct a PET Lusophone teaching course, venue and dates TBD. Course materials have already been translated into Portuguese.

3. Conduct a PET Anglophone teaching course at the 4th AEC Pre-Congress in Kampala, Uganda- August 2019.
4. Conduct a joint IBRO/ ILAE-Africa Anglophone teaching course at the 4th AEC Pre-Congress in Kampala, Uganda- August 2019.
5. To annually support participation of African trainees in epilepsy distance learning courses (e.g. VIREPA, San Servolo) by provision of bursaries.
6. Organize regional epilepsy awareness raising campaigns for English and French speaking countries.
7. Establish epilepsy research needs on the continent.
8. Foster South to South epilepsy-related research collaborations in the region.
9. Increase the number of countries joining the ILAE on the continent.
10. Produce the bi-annual news e-Report, "Epilepsy News Africa."

Angelina Kakooza-Mwesige
Chair, ILAE-Africa

ILAE-Asia and Oceania



Akio Ikeda

Chair

Akio Ikeda (Japan)

Members

Seung Bong Hong (South Korea), Treasurer
Derrick Chan Wei Shi (Singapore), Information Officer
John W. Dunne (Australia), Secretary General
Suryani Guandharma (Indonesia), Information Officer
Byung-In Lee (South Korea), Past Chair
Man Mohan Mehndiratta (India)
Jiong Qin (China)
Ananit Visudtibhan (Thailand)

MC Liaison

Edward Bertram (USA)

Aims of ILAE-Asia Oceania

To develop, stimulate, and coordinate epileptology initiatives in the Asian and Oceanian regions.

Mission of ILAE-Asia Oceania & ASEPA

1. To advance and disseminate knowledge concerning the epilepsies throughout the Asian and Oceanian region.
2. To improve education and training in the field of the epilepsies in Asia via the activities of the Asian Epilepsy Academy (ASEPA).
3. To organize the Asian Oceanian Epilepsy Congresses, together with the International Director of Meetings (IDM) and IBE's Regional Executive Committees.
4. To facilitate clinically relevant epilepsy research in Asia.
5. To serve as a link between the ILAE, IBE, WHO, and regional medical organizations to promote prevention, diagnosis, treatment, advocacy, and care for all persons suffering from these disorders in the Asian and Oceanian region.

6. To promote the activities of local chapters, coordinate policies and administrative structures, and facilitate their involvement within the global ILAE agenda.

7. To review epilepsy services and the size of the treatment gap in each country, and aim to improve the former and reduce the latter.

Newly introduced activities

Epilepsy Surgery Task Force

Chaired by Kensuke Kawai (Japan), Sarat Chandra (India)

- 1) To promote the development of epilepsy surgery in our region, since epilepsy surgery remains markedly underutilized:
 - Educational course of basic skills in epilepsy surgery for young epilepsy surgeons. Primarily use operation videos. Also include interactive live surgery (remote demonstration and interactive discussion).
 - Educational lectures or symposium(s) on indication decision and referral to surgical treatment. Mainly for physicians. 1) and 2) are performed as activities of ASEPA.
 - Research to clarify the treatment gap and barrier to surgical treatment for epilepsy in Asia.
- 2) A strong collaboration with the Asian Epilepsy Surgery Congress (AESC) was discussed on Oct 24, 2018 at AESC, and 'epilepsy surgery center' will be jointly defined by ILAE-AO and AESC.
- 3) Input from epileptologists is essential.

Research Task Force

Chaired by Kheng-Seang Lim (Malaysia)

- 1) Stigma and AED hypersensitivity (Kheng-Seang Lim).

- 2) International study of effects of perampanel on cortical myoclonus (progressive myoclonus epilepsy) has been prepared over the last two years.
- 3) Mentor-mentee program to pair established research teams (such as in Japan, Australia, and Singapore) to new research teams (such as Myanmar, Laos, and Vietnam), done online.
- 4) Training and disease burden.

Continuous activity

1. Teaching the various aspects of epilepsy by means of ASEPA, chaired by John Dunne (Australia):
In 2018, teaching courses (diagnosis, EEG, epilepsy surgery, drug treatment, treatment, etc., usually as a comprehensive course for 1-2 days) were held in many cities and chapters such as India, Mongolia, Taiwan, Singapore, China, and Indonesia. They were successfully conducted with the strong support by the local chapter and its representatives.
2. EEG Certification Exam (led by Shih Hui Lim since 2006):

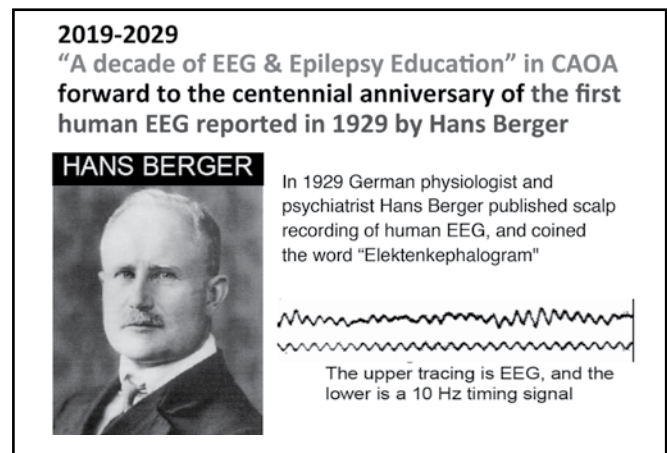
This was primarily a teaching course followed by an exam, and held not only for medical doctors, but EEG technologists were also eligible and competent. More than 400 passed Part I and II examinations over the last ten years. It is co-certified by ASEP and regional medical associations such as ASNA (the ASEAN Neurological Association), i.e., ASEPA- ASNA EEG Certification. Some chapters initially introduced ASEPA EEG Certification, and they later established their own EEG Certification.

3. The Global Campaign Task Force chaired by Ernest Somerville (Australia) and the Training Taskforce, chaired by Chon Tin Tan (Malaysia), have been closely working together.

4. The Pediatric Task Force, chaired by Ananit Visudtibhan (Thailand), is continuing its work.

Recommendations for Future Work

At the time of 12AOEC in Bali, a strategic planning meeting was held on June 27, 2018, and the priority of activities was discussed. In addition to the active, continuous teaching activity in ILAE-Asia Oceania, international collaboration of research activity (combined or compared study among chapters), and clinical interaction and support (genetic diagnosis, MEG examination, etc.) was discussed.



In 2019-2029 "A Decade of EEG & Epilepsy Education" in ILAE-Asia Oceania was announced prior to the centennial anniversary of the first human EEG reported in 1929 by Hans Berger.

Akio Ikeda
Chair, ILAE-Asia and Oceania

ILAE-Eastern Mediterranean Region



Chahnez Triki

Chair

Chahnez Charfi Triki (Tunisia)

Members

Hassan Hosny (Egypt), Past-Chair

Ghaieb Aljandeel (Iraq)

Abdulaziz Ashkanani (Kuwait)

Nihal El Shazly (UAE)

Boulenouar Mesraoua (Qatar)

Adel Misk (Palestine)

Reda Ouazzani Taibi (Morocco)

Management Committee Liaison

Emilio Perucca (Italy)

The ILAE-East Mediterranean Region (ILAE-EMR) was launched in 2004, and includes 14 countries from North Africa, Asia, and the eastern side of the Mediterranean region.

Aims:

The global objective of ILAE-EMR is to improve the management of people with epilepsy. To reach this objective, ILAE-EMR defined specific objectives:

- Promote epilepsy education.
- Promote research on epilepsy.
- Improve involvement of chapters.

STRATEGIC GOALS:

The ILAE-EMR held face-to-face meetings in January and August 2018. The following strategic goals were defined:

1. To collect data from the EMR region.
2. To promote epilepsy awareness.
3. To conduct training in epilepsy and strengthen the educational activities in the EMR.

4. To promote research activities in our region.

5. To increase membership from our region.

ACTIVITIES:

To achieve these objectives, several activities were conducted in 2018:

We began our activities with a business meeting on January 2018 in Casablanca, Morocco. During this meeting, we set up an action plan of our activities. All the members of EMR are aware that training on epilepsy is a main objective; that is why we started our activities with courses on epilepsy for young epileptologists. The first one was held on 27 February to 3 March 2018 in Cairo (Egypt), and was organized by Pr Hassan Hosny. During this course, about 70 young doctors from Egypt, Libya, Tunisia, Algeria, Morocco, and Afghanistan were present. The program included lectures about EEG, clinical, explorations, and treatment of epilepsy. The second course was held in Monastir (Tunisia) and was organized by Pr Chahnez Charfi Triki, in collaboration with the 7th Monastir neurological day organized by Pr Mahboubia Frih Ayed on 18-20 October 2018. This course was conducted in French, and was attended by 25 young medical doctors and one technician from Morocco, Algeria, Senegal, and Tunisia. The program included lectures and practical workshops.

Several other courses were also held jointly with the 16th Pan Arab Union of Neurological Societies (PAUNS) meeting (19 September 2018-Aman, Jordan), 1st Libyan Scientific Society for Epilepsy (13 October 2018, Tripoli, Libya), the 6th UAE Epilepsy Congress (26-27 October 2018, Dubai, United Arab Emirates), the Qatar International Epilepsy School (7-12 November 2018, Doha, Qatar), and during the 3rd EEG & EMG School (16-18 November 2018, Fes, Morocco.)

In order to build a regional leadership, we set up a program of fellowship for young epileptologists, with a priority for the centers of the region. These fellowships will allow these

ILAE-Eastern Mediterranean Region *(continued)*

young people to have advanced training in a particular field of epilepsy and to improve collaboration between the different countries of the region. We received 12 applications from Egypt, Tunisia, Libya, and KSA. Four medical doctors from Egypt, Libya, and Tunisia received fellowships: Ahmed Elkady, Frankfurt Rhein Main University Clinic; Felix Rosenow, Ines Bedou, Timone Hospital; Pr Fabrice Bartolomei, Eman Awen, Kasr Al Aaini University Hospital; Pr Hassan Hosny and Wafa Bouchaala, Necker Hospital; Pr Anna Kaminska.

Also, our EMR is represented in several ILAE commissions:

- ♦ Dr Maria Seddiqui (Qatar), from child to adult. Dr Abdulradha Al Qallaf (Kuwait), from adult to elderly.

- ♦ Young Epilepsy Section: Drs Reem Elayoubi (Saudi Arabia) and Ahmed Elkady (Egypt).
- ♦ Translation of ILAE position papers to Arabic: Fatma Kamoun (Tunisia). Three papers: *Definition of Epilepsy* (2014), *Operational Classification of Seizure Type by ILAE* (2017), and *ILAE Classification of the Epilepsies* (2017), were all translated to Arabic.

Chahnez Charfi Triki
Chair, ILAE-Eastern Mediterranean



Roberto Caraballo

Chair

Roberto Caraballo (Argentina)

Members

Marco T. Medina (Honduras), Past-Chair
Walter M. Camargo Villarreal (Bolivia), Secretary
Mario Alonso Vanegas (Mexico), Treasurer
Patricio Abad (Ecuador)
Mabel Flores (El Salvador)
Lilia Maria Morales Chacon (Cuba)
Juan Carlos Perez Poveda (Colombia)

Management Committee Liaison

Samuel Wiebe (Canada)

Task Force on Research

Fernando Cendes (Brazil) Chair

Task Force on National Programs/Pilot Programs

Mario Carmargo Villarreal (Bolivia), Chair

Task Force on Primary Care

Lilia Morales Chacón (Cuba), Chair

ALADE (Academia Latinoamericana de Epilepsia) Task Force

Alejandro Scaramelli (Uruguay), President
Patricio Abad (Ecuador), Secretary
Elza Marcia Yacubian (Brazil)
Jaime Carrizosa (Colombia)
Loreto Ríos Pohl (Chile)
Guilca Contreras (Venezuela)
Li Li Min (Brazil)
Alicia Bogacz (Uruguay)
Roberto Caraballo (Argentina)

YES- Young Epileptologists

Johann Sebastián Ortiz de la Rosa (Colombia)
Viktor Navarrete-Modesto (Mexico)

Strategic Plan for Latin America

The Strategic Plan for the region was sent to all chapters of the ILAE LA.

Academia Latinoamericana de Epilepsia (ALADE)

Annual Fellowships

The call for Annual Fellowships of the ALADE was made for all Chapters of the ILAE LA through the ILAE's website.

Overall, 28 candidates from 11 different countries applied for the fellowships.

The candidates were evaluated based on a set of preestablished criteria (CV, country of origin, commitment to return to their home country after finishing the fellowship, etc.)

The following three candidates obtained the highest scores and were selected for the training, receiving financial support:

Dr Sofia Dubon (Honduras)

Dr Anilú Daza (Colombia - Venezuela)

Dr Álvaro Sacalxot (Guatemala)

They chose the following centers for their training: 1) UNICAMP, Campinas, Brazil, 2) Hospital Ramos Mejía, Buenos Aires, Argentina, and 3) Clínica Las Condes, Santiago, Chile.

The training centers have been informed. Contact between the centers and the fellows has been established to agree on dates of initiation, etc. Donna Cunard has also been informed.

As in the past, contact with ex-fellows was sometimes lost, so a systematic form was designed in order to maintain follow-up contact with the fellows.

Itinerant Courses (“in-situ”)

ALADE organizes itinerant courses in different locations throughout Latin America. Additionally, pre-convention courses are also held.

This year, the first ALADE itinerant “in-situ” course took place on June within the framework of Epilepsy Week in Tarija, Bolivia. Teachers were Roberto Caraballo, Patricia Braga, Mario Camargo, Tomás Mesa, Carlos Acevedo,

and Franz Chaves. The topic of the course was entitled, 'Epilepsy in Primary Care'

The second "in-situ" course took place in Tucumán, Argentina, on August 31 and September 1. The topic was, refractory epilepsy in children and adults, etiology, and alternative and surgical treatments. The coordinators of the course were Sebastián Fortini and Pedro Nofal. The international speakers were Mario Camargo and Alejandro Scaramelli, while the local speakers were Drs Marcelo Bartuluchi, Oscar Martínez, Alberto Espeche, Santiago Flesler, Gabriela Reyes, and Roberto Caraballo,

The third "in-situ" course took place in Asunción, Paraguay, on November 2. The topic was, Epilepsy in Primary Care, and the teachers were Alicia Bogacz and Roberto Caraballo.

This year, the pre-convention ALADE course was held during the X Latin-American Congress of Epilepsy in Costa Rica on September 29, with a full-day program consisting of the following topics:

The first topic of the day was the new classification of seizures and the epilepsies, coordinated by Elza Marcia Yacubian (Brazil) with presentations by Alicia Bogacz (Uruguay), Elza Marcia Yacubian (Brazil), Lilia Morales-Chacón (Cuba), and Patricia Braga (Uruguay).

The second morning topic was Semiology and a discussion of video cases, coordinated by Alejandro Scaramelli (Uruguay) with presentations by Silvia Kochen (Argentina), Patricio Abad (Ecuador), André Palmieri (Brazil), and Alejandro Scaramelli (Uruguay).

In the afternoon, the first topic was Practical Encephalography, coordinated by Loreto Ríos (Chile) with presentations by Guilca Contreras (Venezuela), Luis Carlos Mayor (Colombia), and Loreto Ríos (Chile).

The course concluded in the afternoon, with the topic of the rational use of new AEDs, coordinated by Jaime Carrizosa (Colombia), with presentations by Jaime Carrizosa (Colombia), Emilio Perucca (Italy), and Alfredo Thomson (Argentina).

XII Latin American Summer School on Epilepsy - LASSE XII

The 12th Latin American Summer School on Epilepsy (LASSE XII) took place in São Paulo from February 15-23, 2018. From 192 applications, 64 participants (62 from Latin American countries and 2 from Angola) participated in all the activities offered by the school.

The central topic of this LASSE edition was "EPILEPSY: The Awakening of Hyperexcitability". The school was designed in such a way that the first two days were centered on discussions related to the mechanisms underlying excitability and hyperexcitability. Prof. Rodrigo Quiñero, from the UK, invited as the keynote speaker, gave the first lecture, which – due to his extraordinary knowledge and didactics – set the right "tone" for the whole school. Another novelty of the program, the case-oriented discussions, were overwhelmingly praised by all participants. As in all editions of LASSE, students were instructed to prepare, in groups and under the guidance of tutors, research projects linked to the theme of the school to be presented on the last day. The dedication and enthusiasm in the preparation of these projects could be observed by all the teachers present. The themes chosen by the student groups were:

Group 1 - Therapeutic efficacy of cannabidiol in patients with focal refractory epilepsy: A multicenter study

Group 2 - High-mobility group box 1 (HMGB1) as a biomarker of epileptogenesis in an animal model of TBI

Group 3 - High-frequency oscillation as a biomarker for seizure recurrence

Group 4 - Does neuropsychological rehabilitation and carbamazepine treatment modify the default mode network in children with self-limited epilepsy?

Group 5 - Neuronal connectivity analysis of interictal spikes and ictal activity in an animal model of TLE

Group 6 - Detection of psychogenic non-epileptic seizures with a multimodal monitoring system

Group 7 - Analysis of the blue lens efficacy in the reduction of interictal epileptiform discharges in the daily lives of patients with juvenile myoclonic epilepsy

Group 8 - Long-term effectiveness and safety of cannabidiol treatment in an animal model of focal epilepsy

All the presentations, organized by the group under the supervision of the tutors, were very satisfactory, denoting the dedication of the “students” to the LASSE proposal. The themes chosen were in line with the topic of XII LASSE and the ensuing discussions involved the participation of all present. The comments and discussions showed a proper understanding of concepts and appropriate reasoning when designing questions and explanations on the topics listed in the projects. The (theoretical) formation of Latin-American networks for the development of projects showed how much still needs to be done with regard to the specific problems in this part of the world. The teachers present at this session enthusiastically participated in the discussions and were unanimous in the positive observation of the potential of these students.

Latin American Epilepsy Online Course for Primary Care

Two online courses were developed by Jaime Carrisoza and Patricia Braga during 2018, with a total of 34 participants. The first course had 13 attendees and the second had 21. Countries of student residence covered the whole region of Latin America (Mexico, Costa Rica, Panama, Cuba, Colombia, Venezuela, Ecuador, Peru, Uruguay and Brazil). This year, we missed students coming from other countries such as Guatemala, El Salvador, Nicaragua, Honduras, Dominican Republic, Puerto Rico, Bolivia, Argentina, and Chile.

During the 10th Latin American Epilepsy Congress in San Jose, Costa Rica, most of the online course tutors met to evaluate the course development and propose future perspectives. Strengths of the course include highly qualified tutors, the updated learning material, good student adherence and the flexibility of the platform. Of importance is the accreditation of the course of eight modules, passing the examination for each module and approving the final exam. Disadvantages are the module agenda (maybe the

course should begin with another more attractive topic than epidemiology), poor communication with tutors in forums, nearly absent interaction with other students, and lower than desired registration rates.

Course changes are being considered and developed for 2019. All tutors and students rated the course as an excellent, competent, and inexpensive strategy that needs wider publicity. Details of the course regarding planning, development, and publication can be found Open Access in *Epileptic Disorders*. Further online courses will be planned during next year to begin in 2020.

Pediatric Epilepsy Training (PET Spanish Version)

Pediatric Epilepsy Training 1 (PET 1) documents and flyers from the British Child Neurology Association (BCNA) were translated from English into Spanish with the commitment of ten child neurologists coming from different Latin American countries. A reverse translation from Spanish to English should be done in 2019. Depending on the funding, it is possible that the first ‘train the trainer’ course of PET 1 will be launched in Bogotá, Colombia next year. Philippa Rodie, representative of the BCNA, in association with ILAE, has presented funding proposals to OPEC and the pharmaceutical industry. Some Latin American chapters are negotiating with local pharmaceutical companies and other NGOs as possible resources for this initiative.

Task Force on Epilepsy in Primary Health Care of the ILAE-Latin America Region

Book Presentation

The book, “Epilepsias en el primer nivel de atención de salud” on epilepsies in first level health care by Lilia María Morales Chacón of Cuba and Sara Silvia Kochen of Argentina has been published this year. The book was presented to the Chapters at the X Latin-American Epilepsy Congress in Costa Rica; all representatives of the chapters present at the General Chapter Meeting received a copy.

Courses of the Task Force for Epilepsy in Primary Care

On June 5-8, 2018, the course of the Task Force for Epilepsy in Primary Care entitled, “Epilepsias in Primary Health Care,” was held in Cuba. The modality was a workshop/

course. Physicians from all provinces of the country, as well as foreign physicians who were doing stages in Cuba, participated.

An instructional video of the course was recorded. On December 4, the course of the Task Force for Epilepsy in Primary Care entitled, "Epilepsies in Primary Health Care," was also held in Buenos Aires, Argentina. The teachers of this edition of the course were Silvia Kochen, Lilia Morales Chacón, and Roberto Caraballo.

Paper Publication

The paper, "Epilepsy for Primary Health Care: A Cost-effective Latin American E-learning Initiative," a report from the Education Commission of the International League Against Epilepsy by Jaime Carrizosa, Patricia Braga, and Marly Albuquerque was published in *Epileptic Disorders (Epileptic Disorders, 20(5), 386-395, 2018)*.

Basic and Clinical Research in Epilepsy

Study on Genetics in Epileptic Encephalopathies

In the study on genetics in epileptic encephalopathies in Latin-America, coordinated by Dr Íscia Lopes-Cendes from Brazil, data is being collected from centers throughout Latin America.

Processing of the material has started.

Study on Cannabis in Epileptic Encephalopathies

In Argentina, a two-year trial has been started for the use of cannabis in epileptic encephalopathies. Public hospitals throughout the country are participating in the study. The study will be a model for the use of cannabis in other countries in Latin America.

Translation of Seminal Articles

The following key articles were translated into Spanish and Portuguese under the supervision of the ALADE:

- ILAE official report: A practical clinical definition of epilepsy: Definición clínica práctica de la epilepsia, Fisher et al., 2014.
- Operational classification of seizure types by the

International League Against Epilepsy: Position Paper of the ILAE Commission for Classification and Terminology: Clasificación operacional de los tipos de crisis por la Liga Internacional contra la Epilepsia: Documento - Posición de la Comisión para Clasificación y Terminología de la ILAE, Fisher et al., 2017.

- Classification ILAE Classification of the Epilepsies Position Paper of the ILAE Commission for Classification and Terminology. Scheffer et al., 2017.

The versions in Spanish and Portuguese can be found in the Spanish section of the ILAE website: <https://www.ilae.org/translated-content/spanish>.

Fellowship in Epilepsy in Canada

A new fellowship was offered by Dr Jorge Burneo at the Epilepsy Program, Western University, London Health Sciences Center.

The fellowship is for a neurologist or child neurologist for the duration of one year with financial support of 50,000 Canadian dollars.

Requirements for the candidates were agreed upon with the center, and a call was made to the chapters and on the ILAE's website.

Dr Miguel Arévalo, neurologist of Ecuadorian and Argentine nationality, was selected for the fellowship position.

Epilepsy Week Bolivia

The IV Epilepsy Week in Bolivia was held this year in Tarija, from June 4-10, with a two-day course on epilepsy, a one-day theoretical-practical on EEG, and a two-day course on epilepsy in primary care, as well as a presentation for relatives of persons with epilepsy. Teachers were Silvia Abente, Carlos Acevedo, Patricia Braga, Roberto Caraballo, Laura Cristino, Franz Chaves, Laura Guilhoto, Oscar Martínez, Tomás Mesa, and Eduardo Medina. In the locations where Epilepsy Week was held in previous years - the cities of Santa Cruz, La Paz, Chuquisaca - local neurologists developed the courses.

Latin American Congress of Epilepsy in Costa Rica

The X Latin-American Congress of Epilepsy was held this year in Costa Rica from September 29 through October 2, with the participation of more than 600 attendees.

- Sam Wiebe was present as the liaison of the ILAE-LA.
- During the Congress, a regional chapter meeting and the commission meeting took place.
- In the commission meeting, the ILAE LA strategic plan was presented and the logo for ILAE LA was discussed.
- Further topics of the meeting were:

• On Education:

- The ALADE
- Curriculum: common competencies for epileptologists, neurologists, pediatricians, pediatric neurologists, clinicians, or psychiatrists
- Primary care (Chair of the task force: Lily Morales Chacón)
- Online courses
- PET courses
- Post-graduate courses in epilepsy, Master's degree
- Consensus: ketogenic diet and cannabis
- The task force on research was established.
Coordinator: Fernando Cendes
- There was an update on the research study on genetics in epileptic encephalopathies by Íscia Lopez Cendes.
- The task force on national programs/pilot programs was established. Coordinator: Mario Camargo

- The Argentine project on telemedicine was presented
- Translation of seminal papers and guidelines was discussed
- Representatives of the YES LA were assigned: Johann Sebastián Ortiz de la Rosa and Viktor Navarrete-Modesto
- Representatives of the YES were proposed for each chapter
- On the first day of the congress, the IBE meeting was held, addressed to the families
- It was decided to hold the next congress in Santiago de Chile in 2020.

Telemedicine

- The Ministry of Health of Argentina issued a decree for a national health program in telemedicine
- Within this program, a model for telemedicine in epilepsy is being developed
- Part of the program was a symposium on telemedicine which was held in Tucuman, Argentina. A second symposium is planned for 2019 in Salta, Argentina
- The experience will serve as a model for future projects throughout Latin America
- Several countries in the region (Brazil, Colombia, México) are already working with telemedicine

Assessment of the Chapters

To assess the functioning of the chapters in the region and the opinion of the chapters on the functioning of the ILAE-LA and the Central ILAE, in order to be able to better respond to the needs, a questionnaire was sent to all the chapters by the end of the year.

The questions were designed in a yes/no fashion so as to make it easier for the respondents, with space for further comments for many of the questions.

The results are currently being collected.

Young Epileptologists - YES

Johann Sebastián Ortiz de la Rosa and Viktor Navarrete-Modesto have been assigned the task of involving the young epileptologists of the YES in the key activities in the region. They will facilitate the work of the YES in Spanish social media to disseminate activities of the ILAE Latin America.

The first achievements of the YES LA are the following:

- Twitter accounts were opened for the ILAE LA in Spanish and in Portuguese, and will be managed by YES members
- Different publications of the ILAE have been translated into Spanish and Portuguese, and published in Facebook
- The infographic material prepared by the YES has been translated into Spanish and Portuguese, and is awaiting a final check by senior members
- Currently, the YES-LA is the section that has the most members, and is the first to organize YES sections in all the chapters of the region
- Three meetings for patients and caregivers took place in Colombia to increase awareness of epilepsy, added to the activities organized by Susana Lara Meier in Costa Rica that are part of the IBE, showing the important participation of the IBE in the YES LA.

- Diego Jiménez, the YES representative of Ecuador, has, together with the local chapter, planned a course to be held in different cities of the country on continuous education and the launch of the YES. This course may be a model to be used by the YES in the region.

Joint Activities with Local Organizations, IBE, and PAHO

On February 28 and March 1 in Trinidad Tobago, a meeting of PAHO, ILAE, IBE, and the Epilepsy Society of the Caribbean (ESC) was held to improve the epilepsy situation in the Caribbean (Improving the Management of Epilepsy and its Comorbidities in the Caribbean. Regional Workshop, Trinidad and Tobago, 28 February – 1 March 2018) with the participation of Marco Tulio Medina and Roberto Caraballo. The aim of the meeting was to identify challenges and opportunities to improve access to services for people with epilepsy in the Caribbean, and to provide countries with tools, evidence, and guidance on best practices to address epilepsy at a primary care level.

A joint strategic plan has been developed for PAHO, ILAE LA and IBE LA. This strategic plan has been submitted for publication in *Epilepsy Research*.

Roberto Caraballo
Chair, ILAE-Latin America

ILAE-North America



Nathalie Jetté

Chair

Nathalie Jetté (USA)

Members

Amy Brooks-Kayal (USA)

Jorge Burneo (Canada)

Dave Clarke (Caribbean)

Sheryl Haut (USA), Past-Chair

Jaideep Kapur (USA)

Karen Parko (USA), Treasurer

Mary Lou Smith (Canada)

Ex-Officio

Taylor Abel (USA), YES Representative

Amza Ali (Jamaica)

Dang Nguyen (Canada)

Page Pennell (USA), AES President

Eileen Murray (USA), AES Executive Director

Management Committee Liaison

Samuel Wiebe (Canada)

The commission's goals are aligned with those of the ILAE, namely to: (1) serve all health professionals as a premier international resource for current and emerging knowledge on epilepsy prevention, diagnosis, treatment, and research; (2) serve as an international information resource and leader for optimal, comprehensive epilepsy care.

Our goals are to (1) continue to contribute to the development of our future epilepsy leaders; (2) contribute to the advancement of knowledge by creating a regional congress; (3) contribute to trainee education by supporting activities such as the Epilepsy San Servolo Summer Course and Leadership Development; (4) continue to address ongoing issues related to approval of antiepileptic drugs with regulators, including the EMA, PMDA, and possibly FDA. These issues include extrapolation of results in adults and children, use of AEDs in monotherapy, shortening placebo exposure through time to event designs; and (5) work with PAHO and relevant stakeholders to advance epilepsy care and education, and implement aspects of the PAHO epilepsy strategic plan in ILAE-NA countries.

Leadership Development Course

The Leadership Development Course, designed to train the next generation of ILAE leaders in essential skills, has been successfully held at the past two IEC meetings. The course is taught by leaders in epilepsy across the world; sessions include strategic planning, budget preparation, negotiations, and personal leadership style. In order to serve specific needs of regional commissions, a course was held in August 2018 at the ILAE Europe meeting in Vienna, Austria. The course was very well received. Another course is planned for 2019 IEC in Bangkok, Thailand. The course is designed and executed in collaboration with the global leadership development taskforce of ILAE, and regional commission chairs.

Recommendations for Future Work

Another Leadership Development course is planned for 2019 IEC in Bangkok.

Global Health Task Force

This was the first year of the Global Health Task Force, which was created with the intent of expanding the scope of Intercommission Educational Outreach. The mission of the task force is to advance epilepsy education and care internationally. The task force has representation from the three chapters in ILAE-NA, as well as representation from the ILAE/IBE Global Outreach Task Force.

In 2018, the task force worked on two reports. The first was the construction of a repository that identifies ongoing global health projects in epilepsy (educational and clinical) that emanate from countries within ILAE-NA. The concept is to identify individuals, countries, and needs to foster communication, collaboration, and the pooling of resources to maximize ILAE global impact. The repository was largely created through two surveys; one based in the United States and one based in Canada. The second report consisted of a review of the literature over the last few years on global health in epilepsy.

Recommendations for Future Work

The plan is to make the repository of global health in epilepsy available as an online resource through the ILAE website.

The first step will be to pilot the success of this online resource with the ILAE-NA projects, after which it will be open to all regions. The repository should allow for collection of data on the design of successful projects and identify specific needs in underserved regions, with the main goal of improving the impact of future projects. The task force would also like to begin to create global health priorities in epilepsy education and care.

Task Force on Regulatory Affairs

The goal of the Task Force on Regulatory Affairs is to monitor key ongoing issues related to approval of antiepileptic drugs with regulators, including EMA, PMDA, and FDA.

Recent ongoing activities have significantly focused on the following issues:

- 1) Due to efforts by the regulatory task force and others, approval for antiepileptic drugs (AEDs) in adults with focal epilepsy can now be extrapolated down to the age of four in the US and Europe, provided that studies are done to support safety and pharmacokinetics. However, studies to demonstrate efficacy are still required for infants down to the age of one month. These studies currently require two inpatient stays in video-EEG monitoring units, making them impractical. The task force has joined forces with the ILAE Pediatric Commission to develop a new trial design specifically for this age group.
- 2) We continue to work with colleagues in the ILAE (specifically the Task Force on Women and Pregnancy) to discuss our concerns about EMA restrictions on the use of valproate in women.
- 3) We are in the process of providing ILAE feedback to EMA regarding their newly released draft guidance.

Recommendations for Future Work

We will continue to work on the new infant epilepsy protocol, with the intent of publishing it. We will be present at the Research Roundtable for Epilepsy taking place March

22-23, 2019 to discuss this and other regulatory issues with both the FDA and EMA. We will address other regulatory issues as they arise. We intend to have a 1:1 meeting with EMA and possibly PMDA in 2020, in Geneva, Switzerland.

PAHO Taskforce

The PAHO taskforce emerged out of the meeting held in Trinidad in March 2018 hosted by PAHO, and to which executive members of the ILAE, members of its Commission on North American Affairs, members of the Latin American Commission and members of the Epilepsy Society of the Caribbean (ESC) were invited. Presentations by Caribbean physicians from several islands led to the identification of shared problems across the region. Having members working in North America in attendance at this meeting highlighted the intention of North America to assist in improving epilepsy care in the comparatively underserved Caribbean. Importantly, having recognised the opportunity for strategic alignment with PAHO's goals and that the longstanding presence of PAHO in the Caribbean region would be helpful in expediting future joint initiatives, the PAHO ILAE Taskforce was formed.

Specific goals for sub-committees established included the following:

- Changing **driving regulations** in the region which presently preclude driving by anyone with epilepsy, regardless of control.
- Formation of local individual **island chapters** of the International Bureau for Epilepsy (IBE) to address social needs of PWE.
- Training of **specialist epilepsy nurses**, initially in Jamaica, to help provide better access to advise and to care of PWE in these islands.
- Identifying **anti-epileptic drugs needed in each island**, and to facilitate their availability, utilising, if necessary, PAHO's strategic funds.

These sub-committees are chaired by ESC members with particular interest in these issues. Since then, Dr Morris Scantlebury has drafted a document for a wider range of anti-seizure drugs for Barbados, which has been submitted to Dr Claudina Cayetano of PAHO. It will be a template for

other islands to produce similar documents for individual islands, as needs differ across the region.

Following this Trinidad meeting, another important development was the approval by the ILAE-NA of a Demonstration Project to address restrictive driving regulations in the Caribbean, beginning with Antigua. It will start by identifying relevant stakeholders, and then to form a team to develop appropriate regulations that can be moved through the legislative process for implementation within the next 2-3 years. Once done, these regulations will be championed throughout the Caribbean Community (CARICOM) for wider regional implementation.

Nathalie Jetté
Chair, ILAE-North America

Recommendations for Future Work

The PAHO Taskforce will continue to work, through its subcommittees, on widening its efforts to include smaller islands which presently are not adequately included in the activities of the Epilepsy Society of the Caribbean. Reinforcing and building relationships with PAHO will be an ongoing strategic objective of this ILAE Taskforce.

Education Task Force

The Education Task Force was tasked in 2018 to begin preparing for the ILAE-NA regional conferences. The task force works in close liaison with the AES, ESC and CLAE to coordinate efforts in planning for those associations' scientific meetings and the regional conferences. The rotations will be in the following order: Canada, US, Caribbean. The next round of regional meetings will be as follows: 1) 2020 – congress in Canada and a smaller session at AES; 2) 2022 – larger session at AES (half or full day; to be determined); and 3) 2024 – congress in Caribbean and a smaller session at AES.

San Servolo Epilepsy Course

The ILAE-NA provided funding for an attendee from a low resource country to attend the San Servolo course. In the future, we will target candidates from the Caribbean region in order to support our efforts to increase knowledge and improve epilepsy care in that region.

Nathalie Jetté
Chair, ILAE-North America

Diagnostic Methods Commission



Sarah Wilson

Chair

Sarah Wilson (Australia)

Members

Sallie Baxendale (UK)
Sándor Beniczky (Denmark)
Ingmar Blümcke (Germany), Past-Chair
Jeffrey Britton (USA)
Paolo Federico (Canada)
Imad Najm (USA)
Sanjay Sisodiya (UK)
Jerzy Szaflarski (USA)
Vinayan K P (Kollencheri Puthenveetil) (India)

MC Liaison

Samuel Wiebe (Canada)

The Commission on Diagnostic Methods provides a significant opportunity for the International League Against Epilepsy (ILAE) to consolidate, and focus standardized protocols and guidelines for diagnosis of the epilepsies and their co-morbidities that is evidence-based and informed by the ILAE classification system of seizure types and their etiologies. Additionally, the Commission aims to promote the optimal use of technology and the identification of new diagnostic methods that will improve the care of patients with epilepsy worldwide.

In broad terms, the Commission seeks to identify key diagnostic methods for epilepsy, while ensuring there is a strong evidence-base for these diagnostic methods, and translating these identified methods into clinical practice. Working towards realising these broad objectives, there are six task forces, each focused on a different domain, including: Neuropsychology, Neuroimaging, EEG, Clinical Genetics Testing, Autoimmunity/Inflammation, and FCD Classification (Neuropathology). In 2018, the Commission has continued to work towards achieving these broad objectives through a range of activities led by the six task forces, as outlined below.

Neuropsychology Task Force

- Successfully held the second ILAE Epilepsy and Neuropsychology Course in Provence, France, in April 2018. This course was designed to provide basic education in the neuropsychological approaches used for the diagnosis and treatment of people with epilepsy. It has now been established as a biennial course, with plans underway to hold this course again in China/India in the spring of 2020. Plans are also underway to hold a course targeting clinicians in the Asian and Oceanian region in Vietnam, in September 2019 (see below).
- Three scientific publications are also in various stages of development, with the first addressing minimum standards for neuropsychological assessment in epilepsy surgery in children and adults, and the remaining two expanding on core competencies described in the new ILAE EpiEd Task Force curriculum.

Neuroimaging Task Force

- Successfully held the annual 2018 International Training Course on Neuroimaging in Epilepsy. This course aims to promote education and training in neuroimaging in epilepsy through providing clinicians and scientists with an understanding of fundamentals and practical skills related to state-of-the-art MRI in epilepsy.
- Continued working towards producing scientific publications, which include guidelines for MRI care in adults with epilepsy, a systematic review on MR negative epilepsy, the essentials of MR, and a neuroimaging case report series. At present, one manuscript is currently under review with *Epilepsia*, while the other three are in preparation for submission in early-mid 2019.
- Ongoing development of a web-based interactive neuroimaging tool, which will feature examples of all

Diagnostic Methods Commission *(continued)*

common epileptogenic lesions organised according to the new ILAE classification system. Once developed, this tool will be freely available to all ILAE members (estimated to be available in early 2019) and will lay the foundation for future content to be developed for a potential web-based neuroimaging course.

EEG Task Force

- ✦ Collaborated with the International Federation of Clinical Neurophysiology (ICFN) to establish a joint ICFN-ILAE Task Force on EEG. This joint task force proposed the development of six essential guidelines to address clinical issues concerning neurophysiology in patients with epilepsy. Of these, four guideline proposals have been successfully submitted and approved, with preliminary literature searches underway. The two remaining guideline proposals are currently being finalised for submission.
- ✦ Facilitated strategic planning and discussion related to a detailed proposal for the development of an international EEG database for education and research, which in collaboration with the ICFN, will be a web-based, interactive digital EEG atlas.
- ✦ Led a number of successful educational initiatives, including the Virtual Epilepsy Academy (VIREPA) courses (i.e., basic, advanced, and paediatric), the fourth edition of the Dianalund Summer School on EEG and Epilepsy, and the first international ILAE EEG in Neonates course, in April 2018. The inaugural EEG in Neonates course covered normal maturational aspects, and abnormal EEG patterns and graphoelements in neonates and infants, as well as the range of seizures and epilepsies encountered in day-to-day practice in the first two years of life.

Clinical Genetics Testing Task Force:

- ✦ Task force members met in 2018 to discuss the current state of clinical genetics testing, and to commence planning for the development of an ILAE report, which will provide recommendations pertaining to the point at which genetic testing is appropriate.

Autoimmunity/ Inflammation Task Force

- ✦ Task force members met regularly throughout 2018

to discuss the definitions of autoimmune epilepsy and amass information that will form the basis for a number of manuscripts planned for submission in 2019.

FCD Classification (Neuropathology) Task Force

- ✦ Successfully held the annual ILAE course on Neuropathology and Epilepsy surgery. This course is designed to enable participants to be better able to recognise and classify various histopathological substrates of pharmaco-resistant epilepsy.
- ✦ Task force members met to discuss recent research developments since the last FCD classification was published in 2011. A plan has been devised for how this classification will be revised, taking into account the available molecular and genetic data, and how their findings will be disseminated going forward.

In 2019 and beyond, the Commission plans to continue working on many of these task force-led initiatives and activities, in line with the overarching goals of the Diagnostic Methods Commission. Task force-led activities in 2019 will include the activities outlined below.

Neuropsychology Task Force

- ✦ A number of educational initiatives, including:
 - The first *Neuropsychological Diagnosis, Management and Treatment of People with Epilepsy* course to be held in Vietnam, in September 2019. This course will be targeted towards neurologists and psychologists who do not have specialist neuropsychological training, and the curriculum will be largely based on the Neuropsychology Task Force's prior two Expectations and Indications (minimum standards) papers.
 - A two-hour workshop based on the task force's *10 Things Paper* at the International Epilepsy Congress (IEC) in June 2019. An application to hold this workshop has been submitted and is currently under review.

Diagnostic Methods Commission *(continued)*

- A symposium at the Fourth African Epilepsy Congress to provide an overview of the role of neuropsychologists in the care of people with epilepsy, and the ILAE resources available to help practitioners in the field. By holding this symposium, the Neuropsychology Task Force hopes to forge links and create a global network of psychologists who can provide input and guidance to the future activities of the Task Force, ensuring it continues to serve the interests of people with epilepsy worldwide. An application to hold this course has been submitted and is currently under review.
- ✦ Continued work to produce a number of manuscripts planned for submission in 2019. These include: (1) guidelines for basic assessment in epilepsy surgery, (2) ten things neurologists should know about neuropsychological assessment in epilepsy, and (3) a case study series to be generated from the teaching course. In addition, discussion will be held regarding future publications on the topics of neuropsychology and intellectual disability, and standards for assessing the impact of antiepileptic medications on cognition.
- ✦ Continued work in the development of a clinical toolkit for neuropsychologists, which will include:
 - Research on predicting outcomes following epilepsy surgery. This will form part of a big data project resulting in its publication, and a freely available algorithm on the ILAE website that all professionals can use to identify pre-surgical patients most at risk of postoperative memory decline.
 - Development of an ILAE approach to standardise the taxonomy of diagnostic outcomes of neuropsychological assessment with clear associated operational definitions of outcomes.
 - Conduction of an international survey of neuropsychological provision in epilepsy services to identify key gaps in existing care, and provide targeted recommendations for improvement.

Neuroimaging Task Force

- ✦ A number of educational initiatives, including the annual International Training Course on Neuroimaging in Epilepsy in May 2019, and a Neuroimaging in Epilepsy Education Day at the IEC in Bangkok in June 2019.
- ✦ Submission of a number of manuscripts for publication in early-mid 2019 (see above for specific details of these), in addition to commencement of planning and development of a freely available Epilepsy Imaging Textbook, which is estimated to be completed by December 2021.

EEG Task Force

- ✦ Continued work with the joint ICFN-ILAE Task Force within the four active guideline workgroups to develop detailed guidelines for clinical practice and improved care of patients. These workgroups include: (1) minimum standards for long-term video-EEG monitoring; (2) minimum standards for recording routine and sleep EEG; (3) automated seizure detection devices; and (4) role of EEG in diagnosing epilepsy in patients with first seizure.
- ✦ A number of ongoing educational initiatives, including the VIREPA course and a second ILAE course on EEG in Neonates. The fifth edition of the Dianalund Summer School is planned to be held in 2020, and will be extended beyond the European region.

Clinical Genetics Testing Task Force

- ✦ Continued work towards producing an ILAE report, which outlines guidelines on management of developmental and epileptic encephalopathies (DEE) in adults.
- ✦ Plan to conduct a global survey of current clinical genetic testing practices to identify key gaps and lay the background for an impending update on guidance for clinical genetic testing in the epilepsies.
- ✦ Commence planning and preparation for an upcoming workshop at the ILAE meeting in Geneva in 2020.

Diagnostic Methods Commission *(continued)*

Autoimmunity/Inflammation Task Force

- Continued work towards producing an ILAE report highlighting the clinical features of autoimmune epilepsy syndromes and diagnostic scoring systems to help identify patients. It is planned that the information from this report will be disseminated over a series of publications, which will be submitted by mid-2019. In addition, the task force is also considering creating an online reference for vignettes, videos, and imaging in autoimmune disorders that would be accessible to ILAE members worldwide.
- Approval has been granted to conduct two symposia on the subject of autoimmune epilepsy disorders at the IEC in Bangkok, in June 2019.

- The development of the classification will be augmented by a three-day FCD summit scheduled for September 2019, where experts in the field (beyond those of the committee) will meet to discuss the topic of FCD in depth. The ensuing lectures and discussions will form part of the justification for the new FCD classification.
- Continued educational initiatives, including the 10th annual ILAE course on Neuropathology and Epilepsy Surgery, scheduled to be held in Brazil in August 2019.

In addition to the above, the work of the Commission and its task forces in 2019 and beyond will rely on collaborative efforts with other ILAE commissions to achieve its goals.

Sarah Wilson
Chair, Diagnostic Methods Commission

FCD Classification (Neuropathology) Task Force

- Continued work towards conducting and publishing the results of scientific studies designed to generate the first update of the FCD classification. A draft of the classification update will be generated in 2019, with final completion and submission to *Epilepsia* estimated for 2020.

Epidemiology Commission



Charles Newton

Chair

Charles Newton (Kenya)

This task force has been delayed whilst the chair is on maternity leave.

Members

Jakob Christianson (Denmark)

Jie Mu (China)

David Thurman (USA)

Ryan Wagner (South Africa)

Epilepsy Registries Task Force

Chair: Jakob Christensen (Denmark)

The aim is to develop a database of registries of epilepsy throughout the world for researchers.

MC Liaison

Sam Wiebe (Canada)

September 2018 to February 2019

The Commission has had two Skype meetings in the last six months.

The work of the Commission is divided into the following task forces:

Psychiatric Co-morbidity Task Force

Chairs: Dale Hesdorffer (USA) and Ruth Otterman (USA)

This is a follow-up from the previous commission. The data has been extracted for systematic review and the paper is currently being drafted by Dale Hesdorffer and Ruth Otterman.

Injuries Task Force

Chair: Jie Mu (China)

The aims of this task force are to conduct a systematic review of injuries in people with epilepsy. The initial searches have been conducted. Several issues are being discussed:

- a. Distinguish between injury 'due' to epilepsy and injury 'related' to epilepsy (e.g. if a patient has a skin rash due to taking AEDs, is this an injury?).
- b. Limiting the co-morbidities to be included (e.g., injury is not directly related to epilepsy, suicide, and SUDEP).
- c. Differentiation between external/internal injuries.

a. Database of Registries based upon work done by Nathalie Jetté has been created.

b. Use data from the European Study of the Burden and Care of Epilepsy (ESBACE) (<https://www.epilepsyallianceeurope.org/programmes/esbace/>).

c. Work on definitions of epilepsy to be used in registries:

I. Number of contacts with hospital (inpatient and/or outpatient), either one or two, or more admission.

II. Prescriptions of anti-seizure medication.

d. The Danish national hospital record was explored; the diagnosis of epilepsy (clinically) was used as the definition of epilepsy. Using two diagnoses increased the validity of the ICD 10 G40 diagnosis for epilepsy. Combination with information on reimbursement for anti-seizure drugs increased the validity further. Estimates were based on various definitions, which will have implication for estimates of burden of epilepsy

Global Cost of Epilepsy Task Force

Chairs: Chuck Begley (USA) and Ryan Wagner (South Africa)

The aim of this task force is three-fold:

- a. To undertake a systematic review of the current literature on the global cost of epilepsy:

Epidemiology Commission *(continued)*

I. A lot of work has been conducted as part of the Chapter for the ILAE/WHO/IBE Global Report for Epilepsy.

II. This work is underway, and databases and terms have been selected.

- b. To develop methods for estimating the cost of epilepsy for all countries.
- c. To generate global and regional estimates of the cost of epilepsy.

Objectives B and C will be developed from the completion of the first objective, which is anticipated to be completed by the end of 2019.

This task force has had three Skype meetings in the last six months and has applied for a budget to hold a meeting in Thailand.

Treatment Gap Task Force

Chairs: Natalie Jetté and Arturo Carpio

The initial aims of this Task Force are to conduct:

- a. A systematic review of the Treatment Gap.
- b. Delphi process for an agreement of the definition of the Treatment Gap.

Discussions involving Nathalie Jetté and Charles Newton have suggested that the terminology of the Treatment Gap needs to re-defined. In particular, expand the definition to include coverage.

The search strategy for articles addressing the treatment gap has been defined and implemented. Titles and abstracts derived from the search have been reviewed for relevance, and current definitions used in the selected articles have been extracted.

Global Burden of Disease Task Force

Chairs: Charles Newton (Kenya) and Natalie Jetté (Canada)

The aim of this task force is to:

- a. Update the prevalence and incidence studies.
- b. Determine the global burden measured as Disability Adjusted Life Years (DALYs).

A paper has been submitted on the global burden using the DALYs. The plan is to update the prevalence and incidence studies.

Databases

The commission has adopted the use of REDCap (<https://www.project-redcap.org/>) for the review of studies within the commission. All the systematic reviews will be conducted with the same format of assessing the quality of the studies and extracting the data into REDCap proformas.

Budget

The 2017 budget was used to support Ryan Wagner and Charles Newton's attendance at the meeting in Washington. The 2018 budget will be used to support David Thurman and Ryan Wagner's travel to the ECE meeting in Vienna. A budget for the IEC meeting in Thailand has been accepted.

Charles Newton
Chair, Epidemiology Commission

Genetics Commission



Holger Lerche

Chair

Holger Lerche (Germany)

Members

Daniel Lowenstein (USA), Past-Chair
Piero Perucca (Australia), Secretary
Annapurna Poduri (USA)

Management Committee Liaison

Helen Cross (UK)

Purpose

- To elucidate the genetic architecture of common and rare epilepsies on a worldwide scale, through large multicenter collaborative frameworks and broad participation by members of ILAE chapters;
- To make the results of genetic research readily accessible to clinicians;
- To give recommendations for genetic testing in daily clinical work;
- To improve the public understanding and knowledge of epilepsy genetics across the world;
- To work with related ILAE commissions to improve education around epilepsy genetics.

Activities

We have had regular Zoom conferences every two months involving the members of the Genetics Commission and the chairs of the associated Task Forces. In addition, we have held a face-to-face meeting at the 13th European Congress on Epileptology in Vienna (28 August 2018). These meetings have also provided the opportunity to finalize the membership of the different Task Forces (see below), through discussions between the Genetics Commission Chair and members, and the elected Task Force Chairs.

Budget

We have obtained funds for meetings (including a face-to-face meeting at the 2019 International Epilepsy Congress in Bangkok), and for support of the Epilepsioeme Project and the new Sequencing Data Sharing initiative.

Planned face-to-face meetings

We will hold a face-to-face meeting at the International Epilepsy Congress in Bangkok on 23 June 2019.

Task Forces

Clinical Genetic Testing in the Epilepsies Task Force

Chair:

Sanjay Sisodiya (UK)

Members:

Hande Caglayan (Turkey)
Katherine Helbig (USA)
Michael Hildebrand (Australia)
Johannes Lemke (Germany)
Piero Perucca (Australia)
Annapurna Poduri (USA)
Lynette Sadleir (New Zealand)
Gagandeep Singh (India)
Yvonne Weber (Germany)
Sarah Weckhuysen (Belgium)

The Clinical Genetic Testing in the Epilepsies Task Force has been focussing on the current position of various aspects of testing in the epilepsies. The remarkable progress in genetic discovery and understanding has raised new challenges and new opportunities. In particular, there is a need to update guidelines on testing, and to address the increasing need to apply testing in adults with severe epilepsies, often of childhood onset, and to raise awareness of the value of testing in this population. As there are gaps in treatment, it is also clear that there are gaps in availability of clinical genetic testing. The Task Force is seeking to raise awareness and provide information on all these areas. For that purpose, articles to educate and provide guidelines for clinical genetic testing in daily clinical practice will be written for ILAE-related journals *Epilepsia* or *Epileptic Disorders*.

Genetics Commission *(continued)*

Genetic Literacy Task Force

Co-Chairs:

Nigel Tan (Singapore)
Daniel Lowenstein (USA)

Members:

Samuel Berkovic (Australia)
Peter de Jonghe (Belgium)
Ingo Helbig (Germany)
Jiang Yuwu (China)
Executive Committee Liaison
Helen Cross (UK)

The Task Force moved the Genetics Literacy series from *Epilepsia* to *Epileptic Disorders* in 2018, as part of an overall repositioning of the series by the ILAE leadership. Two articles in the series (Primer part 2, Genetic Generalized Epilepsies) were published in *Epilepsia* in the first half of 2018. The series then moved to *Epileptic Disorders* in the second half of 2018, kicking off with an editorial highlighting the transition, plus a paper on Genetic Epilepsies with Febrile Seizures Plus (GEFS+). Another manuscript on Pharmacogenetics is currently in review with *Epileptic Disorders* and should be published in 2019. The editors of both journals have been very kind in allowing Open Access to the articles in the series, so that the educational purpose of the series can be achieved. We continue to maintain the online MCQ website (sample quiz here) so that readers can check their learning immediately after reading, or refresh their knowledge days/weeks later.

Publications:

Helbig I, Heinzen EL, Mefford HC; International League Against Epilepsy Genetics Commission. Genetic literacy series: Primer part 2-Paradigm shifts in epilepsy genetics. *Epilepsia* 2018;59:1138-1147. doi: 10.1111/epi.14193.

Mullen SA, Berkovic SF; ILAE Genetics Commission. Genetic generalized epilepsies. *Epilepsia* 2018;59:1148-1153. doi: 10.1111/epi.14042.

Tan NC, Berkovic SF, Lowenstein DH. A new home for the Genetic Literacy series. *Epileptic Disord* 2018;20:456. doi: 10.1684/epd.2018.1022.

Myers KA, Scheffer IE, Berkovic SF; ILAE Genetics Commission. Genetic literacy series: genetic epilepsy with febrile seizures plus. *Epileptic Disord*. 2018;20:232-238. doi: 10.1684/epd.2018.0985.

Epilepsioeme Task Force

Co-Chairs:

Ingo Helbig (USA)
Heather Mefford (USA)

Members:

Roland Krause (Luxembourg)
Kannan Lakshminarayanan (India)
Nigel Tan (Singapore)
Yi Wang (China)
Ahmad Abou Tayoun (USA)

The Epilepsioeme Task Force approached critical tasks relevant to connecting the clinical epilepsy community with the diagnostic arena and revising the language used in the digital space in accordance with the 2017 ILAE diagnostic criteria. The backbone of the Task Force remains the 'Epilepsioeme blog', which is the most frequently read resource regarding epilepsy and genes. In 2018, its overall readership increased steadily from 10,000 to 15,000 views per month, with a new post published every week. Another important activity of the Task Force has been gene curation, which has been carried in collaboration with the ClinGen Epilepsy Clinical Domain Working Group, resulting in the first publication on epilepsy gene curation according to official guidelines (Helbig et al. *Hum Mutat* 2018). Furthermore, the Task Force took up the task of revising the epilepsy-related Human Phenotype Ontology, a digital language for epilepsy phenotypes used by many research groups and clinical laboratories.

Publications:

Helbig I, Riggs ER, Barry CA, Klein KM, Dymont D, Thaxton C, Sadikovic B, Sands TT, Wagnon JL, Liaquat K, Cilio MR, Mirzaa G, Park K, Axeev E, Butler E, Bardakjian TM, Striano P, Poduri A, Siegert RK, Grant AR, Helbig KL, Mefford HC. The ClinGen Epilepsy Gene Curation Expert Panel-Bridging the divide between clinical domain knowledge and formal gene curation criteria. *Hum Mutat*. 2018;39:1476-1484. doi: 10.1002/humu.23632.

Genetics Commission *(continued)*

ILAE Consortium on Complex Epilepsies

Chair:

Samuel Berkovic (Australia)

Members:

Larry Baum (Hong Kong)

Russ Buono (USA)

Gianpiero Cavalleri (Ireland)

Hakon Harkonarson (USA)

Erin Heinzen (USA)

Michael Johnson (UK)

Reetta Kälviäinen (Finland)

Bobby Koeleman (Netherlands)

Roland Krause (Luxembourg)

Patrick Kwan (Hong Kong / Australia)

Holger Lerche (Germany)

Iscia Lopes-Cendes (Brazil)

Daniel Lowenstein (USA)

Terence O'Brien (Australia)

Sanjay Sisodiya (UK)

There has been considerable progress over the last 12 months. A major analysis of over 15,000 subjects with epilepsy was completed, largely due to work driven by Remi Stevelink in Bobby Koeleman's lab and Mark McCormack working with Gianpiero Cavalleri. This has resulted in an important paper published in December 2018 in *Nature Communications* which has demonstrated 15 loci for common forms of epilepsy and represents a major advance compared to our initial analysis in 2014. The report received a large amount of publicity and it has generated enthusiasm for even larger studies and the utilization of polygenic risk scores in epilepsy. In 2019 we expect that the sample size will grow to in excess of 25,000 subjects with epilepsy and the 3rd analysis will be done driven largely from the Cleveland Clinic laboratory headed by Dennis Lal.

Publication:

International League Against Epilepsy Consortium on Complex Epilepsies. Genome-wide mega-analysis identifies 16 loci and highlights diverse biological mechanisms in the common epilepsies. *Nat Commun* 2018;9:5269. doi: 10.1038/s41467-018-07524-z.

Task Force on Sequencing Data Sharing

Chair:

Holger Lerche (Germany)

Members:

Samuel Berkovic (Australia)

Gianpiero Cavalleri (Ireland)

Ingo Helbig (Germany)

Roland Krause (Luxembourg)

Daniel Lowenstein (USA)

Kevin McKenna (USA)

Sanjay Sisodiya (UK)

Kate E. Stanley (USA)

A new Task Force on Sequencing Data Sharing has been formed with the goal to bring together as many sequencing data as possible from patients with genetic epilepsies across the world. This activity will be similar to the very successful ILAE Consortium on the Genetics of Complex Epilepsies which collected such data for genome-wide association studies. There are already more than 25,000 whole exome sequencing datasets available from large collaborative studies performed in the US, Canada, and in Europe. The TF is currently exploring the possibilities to bring all data together and make them accessible for joint data analysis to the community including appropriate controls. The goal is to have this new platform running in 2020.

Medical Therapies Commission



Kimford Meador



Dong Zhou

Co-Chairs

Kimford Meador (USA)

Dong Zhou (China)

Members

Patrick Kwan (Australia)

Sanjeev Thomas (India)

Tim Welty (USA)

Management Committee Liaison

Emilio Perucca (Italy)

Access to Medicines & Treatment Gap Task Force

1. The Access to Medicine and Treatment Gap Task Force had its first Web Conference on 10 October 2017, where an initial work plan was presented and discussed. The proposed plan was to collect data from ILAE member countries on completed or ongoing strategies, projects, and interventions to improve access to medicines to include initiatives on legislation, distribution and logistics, availability, pricing, quality control, and prescribing regulations.
2. During the 2nd Web Conference on 5 February 2018, the majority of the task force members proposed and agreed to start collecting information on access to antiepileptic drugs in their respective countries, and from neighboring countries in their own region, in order to create a map relating to “access to medications.” The Survey on Access to AED has started and is still in progress. The questionnaire was sent to all ILAE Chapters (not only in LMICs and LICs). We had answers from 79 Chapters: 34 from HICs, 18 from UMICs, 19 from LMICs, and eight from LICs. The initial results are interesting, but it is evident that the data is affected by the inequality of the number of chapters across HICs, MICs, and LICs included in the survey. For this reason, the task force is planning to extend the survey to colleagues working in countries without ILAE/IBE Chapters through the network of the Regional

ILAE Committees. The task force is going to present the preliminary result of the survey at the International Epilepsy Congress in Bangkok

Botanicals & Traditional Medicines

1. The task force is working to expand its website with a listing and description of multiple botanicals. They are exploring information on traditional medicines.
2. A symposium on basic science and clinical experiences with Cannabidiol will take place at the German/Austria/Switzerland regional epilepsy conference in Basel, Switzerland on May 8-11, 2019.
3. As a first anticonvulsant of botanical origin, Cannabidiol has been licensed for medical use in the USA under the trade name Epidiolex, by the British company GW Pharmaceuticals. Licensure in Europe is anticipated for 2019.

Dietary Task Force

1. A Dietary workshop is scheduled for 1 July 2018, the last day of AOEC in Bali, Indonesia, supported by the ILAE.
2. Other dietary workshops are also done and planned in this year in Myanmar in March, Bandung, Indonesia in July, Ulaanbaatar, Mongolia in August, and at least one of those workshops will be supported by the ILAE.
3. A strategic task force business meeting is scheduled for 4 October 2018, one day prior to the 6th Global Symposium on Ketogenic Therapies in Jeju, Korea, which is also approved by the ILAE with financial support.
4. Dozens of clinicians and investigators around the world participated in the revised ketogenic diet

Medical Therapies Commission *(continued)*

consensus statement, which was recently published in *Epilepsia Open*, and which provides updated guidelines for implementing dietary therapies for epilepsy in a safe and effective manner.

5. Dietary Task Force was joined with the organizing committee of “The 6th Global Symposium on Ketogenic Therapy”, 5-9 October 2018, and was endorsed by the ILAE. The anticipated attendance for this premiere biennial meeting is approximately eight hundred individuals from around the world.

2. Another group has been working on development of a survey to be sent to ILAE chapters and members. The survey is based on one that was developed by our South American colleagues, as they attempt to address issues of generic substitution in that part of the world. It is designed to help understand the challenges faced in various parts of the world, with the intent of guiding our task force as we develop final products.
3. The task force held a face-to-face meeting during the European Congress on Epileptology in Vienna, Austria.

Emergency Treatment

The task force continues work on producing two evidence-based guidelines:

1. European Guidelines in conjunction with the EAN; and
2. Guidelines for resource poor countries.

Epilepsy in the Elderly

At a teleconference in March 2018, the Task Force on Epilepsy in the Elderly decided to divide responsibility for different aspects of this subject. Individuals volunteered to work on epidemiology and scope of the problem, etiology and pathophysiology, treatment including medications and surgery (interfacing with Surgery Task Force), and prognosis. A literature review is in progress with collection and sharing of references by category via box.com.

Generic Medications

1. A group has been working on the development of a manuscript that will serve an informational and educational basis for understanding generic substitution. This manuscript will help provide a strong background of understanding on the concepts of generic substitution and issues faced in various parts of the world. Our hope is that the group will have a draft manuscript by the European Congress at the end of August 2018.

Psychology

The current goal of the task force is the investigation of barriers to psychological treatment in people with epilepsy. For this purpose, a survey has been drafted and endorsed by the Psychiatry Commission. The survey has been successfully piloted in Australia and we are about to submit an ethics amendment to conduct the survey globally. The Psychology Task Force will also conduct an interactive forum session at the IEC in Bangkok to present and discuss case-based educational activities that relate to the International Epilepsy Curriculum. In addition, the Psychology Task Force is designing an ILAE webpage to provide resources on psychological treatments.

Regulatory Affairs Task Force

We held a very successful session and a general discussion on the regulatory aspects of antiepileptic drug (AED) development during the most recent European Congress on Epilepsy in Vienna. The session was attended by task force members, as well as members of the European Medicines Agency, and Health Canada. Agenda items included: revision of the EMA guidelines on AEDs, extrapolation from adults to children (and from children to adults), and what remains to be done (age range, seizure types, syndromes). New outcome measures: time to event, composite endpoints on seizures (frequency, severity, sleep or awake), composite end points on seizures and comorbidities, and choice of the endpoints (trial population: seizure types within a

Medical Therapies Commission *(continued)*

given syndrome or seizure type(s) across syndromes). As a result of this meeting, the Regulatory Affairs Task Force, in collaboration with the Pediatric Epilepsy Research Consortium (PERC) and the Pediatric Commission of the ILAE, created a novel trial design intended to address concerns about conduct of infant trials of new therapeutic agents. This trial design is now being considered by the EMA and FDA.

Women/Pregnancy

The Task Force has carried out a survey of available guidelines for the management of epilepsy in pregnancy in

the ILAE Chapters. To date, 73 chapters have responded and the results are currently being analyzed. The task force is currently working on a review on epilepsy and pregnancy intended for *Epileptic Disorders*. Drafts of some subsections have been written. This series of articles are also intended for adjustment to be suitable for publication on Wikipedia.

Kimford Meador
Co-Chair, Medical Therapies Commission

Neurobiology Commission



Aristeia Galanopoulou

Chair

Aristeia Galanopoulou (USA)

Members

Marco de Curtis (Italy), Past-Chair

Terence O'Brien (Australia)

Kathryn Davis (USA), Marcio Moraes (Brazil)

Management Committee Liaison

Edward Bertram (USA)

Purpose

To promote neurobiology research in epilepsy through advocacy, education, training, proposals of optimal methodologies, and infrastructure improvements.

Activities

We have had zoom conferences with the members of the Neurobiology Commission (NBC) and the chairs of its task forces (TF) regularly, and also held face-to-face meetings in the ECE at Vienna (August 26, 2018) and AES meeting in New Orleans (December 4, 2018). The membership of the NBC TFs has since been finalized through discussions between the NBC chair, the elected TF chairs, and the leadership of both the ILAE and the AES in regard to the ILAE/AES Joint Translational TF (see below for details). The following have been achieved and discussed:

NBC Symposia at ILAE congresses:

1) NBC symposium in the ECE at Vienna, 2018 (completed).

“Does coffee/caffeine consumption influence seizures and epilepsy?”

Date: August 26, 2018

Chairs: Astrid Nehlig and Aristeia Galanopoulou

Speakers:

- Detlev Boison (USA): *“Mechanisms of action of caffeine in the brain and potential proconvulsant properties of caffeine”*

- Astrid Nehlig (France): *“Interindividual variability of caffeine metabolism and circulating levels”*

- Christophe Bernard (France): *“Consequences of early life caffeine exposure on brain development and susceptibility to seizures”*

- Christian Samsonen (Norway): *“Does coffee/caffeine consumption influence seizure activity in individuals with epilepsy?”*

2) NBC symposium in the IEC in Thailand, 2019 (planned).

“Biological rhythms that modulate the risk of seizures”

Date: June 23, 2019 from 12:00-14:00

Chairs: Christophe Bernard and Aristeia Galanopoulou

Speakers:

- Maxime Baud (Switzerland): *“Rhythms modulating seizure risk in human epilepsies”*

- Philippa Karoly (Australia): *“Circadian control of seizures and seizure forecasting”*

- Christophe Bernard (France): *“Circadian regulation in the pathophysiology and treatment of temporal lobe seizures”*

- Judy Liu (USA): *“Loss of CLOCK underlies focal epilepsies”*

Workshop funding through the NBC

NBC has co-sponsored the following two workshops:

- Gordon research conference: *“Mechanisms of epilepsy and neuronal synchronization”* (August 2018) by Drs Bernard and Brooks-Kayal, for the amount of \$6,000 due to parallel funding received by the North American Commission. The recommendation that workshop funding in the future would require ILAE participation in the topic selection was communicated to the organizers, per ILAE EC decision. Further, the NBC recommendation was that funds should preferably go

Neurobiology Commission *(continued)*

towards applicants from low-income countries and a report was requested at the conclusion of the meeting.

- 2nd Latin-American Workshop on Neurobiology of Epilepsy: “Cannabinoids and epilepsy, myths and realities”. Organizer: Luisa Lilla Rocha Arrieta. Funding for \$6,200 was recommended by the NBC and further approved by the ILAE EC. The same recommendations were communicated to the organizer.

Further, we have revised the workshop application for funding to include the expectation that ILAE should be involved in topic selection of meetings for which support is requested.

We also proposed for budget approval for 2019 that “ILAE bursaries of the NBC” administered by the NBC may be given for travel awards for trainees or early career investigators with limited resources who apply to cover travel expenses to attend high quality scientific meetings, training opportunities, or workshops that are not sponsored or organized by the ILAE.

Statement regarding Professor Nikos K Logothetis:

The NBC discussed the case of Professor Nikos Logothetis in the context of its history and implications for the public perception of the way and purpose of animal use in biomedical research, and agreed to post the following statement on its website (<https://www.ilae.org/about-ilae/topical-commissions/commission-on-neurobiology>):

“The Neurobiology Commission of the International League Against Epilepsy (ILAE) supports and values the importance of the research that Professor Logothetis’ group has been conducting to advance our understanding of brain function, and to develop better interventions that may eventually help to manage individuals with neurologic diseases. We also strongly support the international scientific efforts that advocate for the adoption of ethical and humane practices, and endpoints in animal biomedical research, as suggested for Professor Logothetis’ case by animal protection officers of the Max Planck Institute for Biological Cybernetics.

The scientific community has experienced cases when unjustified accusations or attacks have negatively impacted

the lives and work of colleagues, despite their adherence to the accepted standards of ethical animal experimentation. We therefore urge careful and impartial review of the facts and circumstances to reach a responsible and objective resolution of the case of Professor Logothetis, in a manner that respects individual human rights and our societal ethical standards.”

Budget

We have submitted a budget request for this year for \$15,000 for meetings of the NBC in the IEC in Thailand (June 2019). We also requested funds for the proposal to create ILAE bursaries of the NBC to support trainees or early career investigators with limited resources who apply to cover travel expenses to attend high quality scientific meetings, training opportunities, or workshops that are not sponsored or organized by the ILAE.

Planned face-to-face meetings

We are planning a face-to-face meeting in Bangkok and at the AES meeting in Baltimore, MD.

WONOEP Task Force

Co-Chairs

Terence O’Brien (Australia)
Aristea Galanopoulou (USA)

Members

Marco de Curtis (Italy), Past-Chair
Ozlem Akman (Turkey)
Marcia Moraes (Brazil)
Tomonori Ono (Japan)
Raman Sankar (USA), liaison to Advocacy TF of the NBC

Aim

Organize the WONOEP meetings prior to the IECs. The next one planned is for Thailand (June 2019).

WONOEP 2019

The TF has selected the following topic for the next WONOEP: “What is a seizure?” The meeting will run as a workshop, with the plan to discuss current definitions, limitations, and proposals submitted with the intent of

Neurobiology Commission *(continued)*

producing position papers to better define seizures across the lifespan, whether focal or generalized or unclear, and attempt to define the borders between epileptic and nonepileptic paroxysmal disorders resembling seizures. Following a request for abstract submissions, we received numerous abstracts which have been scored by the WONOEP TF and NBC members, and invitations will be sent shortly. The programme of the WONOEP has been discussed at the AES meeting of the WONOEP TF and NBC. In parallel, we have been seeking additional funding to fill the needs for this meeting.

For the selection of the local resort and the negotiations with the candidate resorts, the TF has been working closely with the local organizers (Drs Oranee Sanmaneechai and Kanitpong Phabphal) recommended by Dr Anannit Visudtibhan from the local chapter. In addition, Richard Holmes, Philippa Scott, and Denis McEvoy from the congress bureau have been invaluable in representing us in the negotiations for the best contract terms for the resort that will accommodate the WONOEP participants. We have elected to have the WONOEP 2019 in Ayutthaya, the old capital of Thailand, at the Krungsri River Hotel, on June 16-20 2019, which offers the possibility to have a small-scale workshop (~60 people) encouraging informal interactions, in a historical and cultural location, with a more affordable budget.

The deliverables of the workshop will include position papers formulated by the discussions and presentations of the selected topic.

Budget

There is a budget of \$40,744, which includes the carryover from previous years (funds from ILAE as well as the Harinarayan family) as well as an additional \$15,000 donated by UCB for the WONOEP meeting. This budget is expected to also cover the Harinarayan Young Investigator awards. Thanks to Dr Raman Sankar, the Harinarayan family has graciously donated an additional sum of \$20,000 for the purpose of supporting the WONOEP meeting and the Harinarayan Young Investigator awards given by the NBC to young presenters of the best original science abstracts at the IEC meetings. Additional funds have been

requested by ILAE to cover the expected costs of the meeting (to be decided).

ILAE/AES Joint Translational TF

Members

The membership of the ILAE/AES joint Translational TF has been confirmed and consists of the following:

AES Co-Chairs:

Aristea Galanopoulou (USA) and Greg Worrell (USA)

AES Nominees:

Richard Staba (USA), Anne Anderson (USA), Manisha Patel (USA), Kevin Kelly (USA)

ILAE Co-Chairs:

Terence O'Brien (Australia) and Matthew Walker (UK)

ILAE Nominees:

Gunther Sperk (Austria), Rudiger Koehling (Germany), Heidrun Potschka (Germany), Steven Petrou (Australia)

Liaison to MC:

Ed Bertram (USA)

Initiatives

We have had several zoom conferences to discuss the initiatives that our TF will undertake during the coming cycle, as well as the selection of new working group (WG) members to assist with these initiatives. The following were agreed upon as initiatives and new volunteer members for the WGs were proposed, approved, and invited by the ILAE/AES leadership:

- (a) Continue the work of the TASK1 group with the following goals during the upcoming cycle:
 - TASK1-WG (*working group*) on *classification of seizures and epilepsies in rodents*. These TASK1-WGs will include:
 - Creation of a public access online Atlas of Rodent EEGs through collaboration with our TF members, and TASK1-WG members and system analysts (Peter Shen).

Neurobiology Commission *(continued)*

- Classification and interpretation of abnormal and epileptic EEG patterns, and behavioral seizures. Eventually, this will also help the organization and will provide content for the Atlas of Rodent EEGs (see below).
 - Working classification of rodent seizures and epilepsies in a manner that could translate to human seizures and epilepsies. In this effort, we will consider EEG, seizure phenotype, comorbidities, and other characteristics (pathology, imaging, genetics, etc.).
- (b) Continue the work of the TASK2 group, by extending the term of the existing TASK2 working group that aims to complete the systematic review of the animal epilepsy studies on outcome measures (led by Drs Simonato, Brooks-Kayal, and Jensen).
- (c) Continue the work of the TASK3 group on preclinical common data elements (CDEs) in epilepsy by:
- (i) expanding the topics of the CDEs (e.g., on pathology, omics, epilepsy phenotyping of animal models, imaging, etc.)
 - (ii) considering methods to make these tools accessible to most labs (e.g., software or databases)
 - (iii) undertaking efforts to disseminate the preclinical CDEs and create a publicly available set of database modules with the existing CDEs through an agreement with LONI (U South California)

Publications and other initiatives from past cycle activities:

- (a) Special issue on preclinical CDEs by TASK3 has been published in *Epilepsia Open* (TASK3): The special issue has been published (*Epilepsia Open* 2018, vol3, S1) and has been placed online for community feedback that was invited with email blasts from ILAE, AES, NINDS, CURE, and the ILAE/AES Joint Translational Task Force: <https://www.ilae.org/cde-discussion>
- (b) “Methodologic recommendations and possible

*interpretations of video-EEG recordings in immature rodents used as experimental controls: A TASK1-WG2 report of the ILAE/AES Joint Translational Task Force” (Akman, Raol, Auvin et al): Published in *Epilepsia Open* (2018): <https://onlinelibrary.wiley.com/doi/10.1002/epi4.12262>*

- (c) TASK1-WG4 report on “How do we use *in vitro* models to understand epileptiform and ictal activity? A report of the TASK1-WG4 group of the ILAE/AES Joint Translational Task Force” (Dulla et al): Published in *Epilepsia Open*: <https://onlinelibrary.wiley.com/doi/10.1002/epi4.12277>
- (d) We have been discussing with other organizations plans to share the CDEs with them for use by team science/consortia research groups, e.g., CURE (Traumatic Brain Injury (TBI) initiative).

Budget

We had received approval of a budget request for 2018 by both AES and ILAE, with matching fund requests (\$15,000 each) for face-to-face meetings. We have received approval to utilize the existing balance (carryover of \$27,814) toward planning the above initiatives (e.g., databases/software for TASK3 CDEs, website construction for the Atlas by TASK1). The TF’s 2019 budget request included a request to carry over the funds for the purpose of face-to-face meetings in 2019 (IEC, AES) and the above two planned projects.

Planned face-to-face meetings

We are planning for a face-to-face meeting in Bangkok and at the AES meeting in Baltimore.

Genetics/Epigenetics TF:

Chair

David Henshall (Ireland)

Members

Katsuhiro Yamakawa (Japan)

Albert Becker (Germany)

Chris Reid (Australia)

Neurobiology Commission *(continued)*

Alica Goldman (USA)
Erwin van Vliet (Netherlands)
Ischia Lopes-Cendes (Brazil)
Annapurna Poduri (USA)
Michael Johnson (UK)
Hela Mrabet (Tunisia)
Katja Kobow (Germany), liaison to Big Data TF
Steven Petrou (Australia), liaison to ILAE/AES Joint Translational TF

Aims

Discuss scientific and clinical research priorities of the TF and commission review(s) that would focus on promoting the TF; promote priority Genetics-Epigenetics topics at key epilepsy meetings; organize training, create infrastructure, and promote industry-academia research interactions and developments; and collaborate with the ILAE/AES Joint Translational TF on CDEs in genetics-epigenetics.

Activities

The TF has held teleconferences to discuss the priorities and manuscripts to prepare. Planned TF manuscripts include primers on epigenetics and genetics for the epilepsy community. Some of these will include educational material targeting an audience with a more general interest and for these there was a discussion to consider either the educational journal of the ILAE (Epileptic Disorders) and/or Wikipedia. The TF also has liaisons from other ILAE TFs and commissions to avoid overlap with initiatives planned from other sources.

Young Neurobiologists TF:

Co-Chairs

Premysl Jiruska (Czech)
Stephanie Schorge (UK)

Members

Joseph Raimondo (S. Africa)
Kathry Davis (USA)
Nigel Jones (Australia)
Liankun Ren (China)
Vadym Gnatkovsky (Italy)
Shilpa Kadam (USA)

Nihan Carcak (Turkey)
Erwin van Vliet (Netherlands)
Christos Panagiotis Lisgaras (Greece), liaison to Next Generation Task Force and Young Epilepsy Section (YES)

Aims

- To evaluate the current environment for attracting, sustaining, and advancing talented young neurobiologists in epilepsy research across regions, cultures, and genders, as well as to identify areas in need of improvement, challenges, and possible solutions.
- To promote opportunities that will cultivate leadership qualities and identify future young leaders among young epilepsy neurobiologists.
- To collaborate with the other members of the NBC and its TFs, so as best to integrate the expertise of this TF in the initiatives and goals of the NBC and its TFs.

Activities

Task 1: *To evaluate the current environment for attracting, sustaining, and advancing talented young neurobiologists in epilepsy research across regions, cultures, and genders, as well as identify areas in need of improvement, challenges, and possible solutions.*

Members involved: Kadam, Schorge, Raimondo

Proposed first-year deliverables

- (a) Definition of positive and negative factors which determine the career trajectory by the members of the TF. Definition of the regional differences.
- (b) Preparation and design of a survey to identify positive and negative factors amongst successful and failed epilepsy research fellows.
- (c) Contact of agencies, societies, and charities involved in epilepsy research to create a list of suitable candidates for the survey.

Neurobiology Commission *(continued)*

Progress in 2018

During the first year, the YNTF has designed two types of surveys based on repeated discussions. The first survey targets young investigators who are at the crossroads to becoming independent scientists. The survey questions focus on the identification of the critical parameters that determine the success or failure in securing long-term (or permanent) positions. The second survey aims at senior principal investigators (PIs) who are potential employers of young neurobiologists. **The goal of the survey is to identify key features which can be controlled or influenced by the activity of the ILAE.** We have performed the pilot survey amongst the junior participants at the Gordon Research Conference in 2018. Currently, the survey is being modified based on the feedback. We have negotiated with multiple agencies and organizations to distribute the survey amongst the research fellows and senior scientists. The pathways to distribute the surveys will include the ILAE website, ILAE newsletter, AES meeting web page, YES website, and YES database of young neurobiologists using Facebook and other social media. Organizations like the Epilepsy Foundation or Epilepsy Research UK, which provide fellowships, will be approached as well.

Second-year deliverables

- (a) The analysis of the survey results.
- (b) The identification of the factors that can be influenced by the ILAE to promote young neurobiologists. The proposal of strategies and specific steps how to influence the controllable factors.

Task 2. *To promote opportunities that will cultivate leadership qualities and identify future young leaders among young epilepsy neurobiologists.*

Members involved: Davis, Ren, Jones

Proposed first-year deliverables:

- (a) Definition of specific aspects and needs required for leadership training and career development for

young epilepsy neurobiologists. Recommendations for their implementation into ongoing leadership and mentoring programmes. Explored needs for separate training programs targeting only neurobiologists.

- (b) Negotiated increased number of neurobiologists participating at Leadership programmes organized by ILAE (in collaboration with leadership TF).
- (c) Identification of possible sources for funding the career development programmes (EU, USA, regional).
- (d) Setup joint collaboration with other TFs and definition of the role of Young Neurobiologist TF in the activities of collaborating TFs.

Progress in 2018

To synergize the work with other TFs, we have liaised with the Next Generation TF, Leadership TF and YES. Liaisons from YNTF regularly participate at the teleconferences of these groups. Dr Gnatkovsky participated at the kick-off meeting of the YES. The YNTF will become an advisory body for the initiative of other task forces, which aims at the larger epileptological community. YNTF provide advice and support for these initiatives from the perspective of basic science and experimental epileptology. These initiatives will include leadership and mentoring programmes, translational forums at the major ILAE meetings training. Based on multiple feedback, one of the key strategies to cultivate young neurobiologists is to teach them how to effectively communicate science to clinicians and increase the awareness of the translational potential of their research, and improve the communication with clinicians in general.

Second-year deliverables

- (a) Analysis of the feedback on the latest leadership training and mentoring programmes.
- (b) Increased promotion of the leadership and mentoring programmes amongst young basic scientists.

Neurobiology Commission *(continued)*

- (c) Increase the promotion of the sessions at which young neurobiologists will actively participate (in collaboration with YES).

Task 3. To collaborate with the other members of the NBC and its TFs so as best to integrate the expertise of this TF in the initiatives and goals of the NBC and its TFs.

Members involved: Gnatkovsky, van Vliet, Carcak, Lisgaras

First-year deliverables

- (a) Defined paths and strategies to increase the advocacy of neurobiology at international and regional levels.
- (b) List of key factors which are required to increase the involvement of young neurobiologists at the international meetings and definition of strategies how to communicate better, as well as increase the attractiveness of, and advocate the importance of, basic and translational epilepsy research to the wider epileptological community at the meetings. Identification of positive and negative aspects of how the basic science is perceived from a clinical perspective.
- (c) Paths and plan for wider utilization of social media to effectively communicate important information and recommendations amongst the young neurobiologists (Facebook, Twitter, webinars).

Progress in 2018

Based on multiple feedback, one of the key strategies to cultivate young neurobiologists is to teach them how to effectively communicate science to clinicians, and increase the awareness of the translational potential of their research and improve the communication with clinicians in general. In collaboration with other task forces, we coordinated the strategies for the increased involvement of young epileptologists at conferences and workshops organized by ILAE.

Second-year deliverables

- (a) The elaboration of steps on how to improve communication between basic scientists and clinicians.

Networks TF:

Chair

Christophe Bernard (France)

Members

Serge Vulliemoz (Switzerland)
Liset Menendez de la Prida (Spain)
John Terry (UK)
Alon Friedman (Canada/Israel)
Chou-ching Lin (Taiwan)
Joao Pereira Leite (Brazil)
Ivan Soltesz (USA)
Patrick Forcelli (USA)
Greg Worrell (USA)

Management Committee Liaison

Ed Bertram (USA)

Aims

To evaluate the current infrastructure, strategies, and advances in knowledge on understanding epilepsies as network disease(s) so as to best integrate them in efforts to accelerate and optimize research towards understanding the neurobiology of epilepsies and comorbidities and the development of better therapies. To collaborate with the other members of the NBC and its TFs, to integrate the expertise of this TF in the initiatives and goals of the NBC and its TFs.

Advocacy TF of the NBC:

Co-Chairs

Raman Sankar (USA)
Solomon (Nico) L. Moshé (USA)

Members

Terence O'Brien (Australia)
Vicky Whittmore (USA)
Akio Ikeda (Japan)
Janet Mifsud (Malta)
Kathryn Davis (USA)
Management Committee Liaison
Ed Bertram (USA)

Neurobiology Commission *(continued)*

Aims

- ♦ To evaluate the current funding environment for neurobiology research in epilepsy.
- ♦ To advocate for the value of neurobiology research in improving knowledge of epilepsy and translating basic science discoveries to better therapies.
- ♦ To advocate for initiatives that will improve research infrastructure and the initiatives of the NBC and its TFs, including research, educational, and training initiatives.
- ♦ To advise the NBC and the Research Advocacy TF on matters related to advocating for neurobiology research.

Activities

The advocacy TF along with the NBC have explored opportunities for collaboration with other ILAE or external organizations of task forces/committees to build support for neurobiology epilepsy research. The advocacy TF will also advise and work with NBC on identifying best ways for advocating for epilepsy research to the public, scientific organizations, and policymakers. In summary, the following has been done:

Initial work has focused on giving the epilepsy patient and caregiver community access to translational neurobiology research. The task force decided to work with Living Well with Epilepsy, a blog run by Jessica Kennan Smith.

Thus far we have:

1. Met with Jessica Keenan Smith on multiple occasions to plan the most effective Neurobiology blog.
2. Established an ILAE Neurobiology Commission email to be used for the blog.
3. Determined that we will aim to post monthly blogs on the *Living Well with Epilepsy* website from 400-1000 words. We will focus on the following:

- a. Given that the typical user is a woman, aged 25-45, living well with epilepsy or caring for a person with epilepsy, we will ensure that women are focused in videos in addition to focusing on diversity

4. Potential initial topics:

- a. Caffeine (first topic – we have reached out to Dr Nehlig with interview questions)
- b. Bone health
- c. Biological rhythms: menstrual cycle, multidien research
- d. Plan to engage other task forces:
 - i. Genetics/Epigenetics TF
 - ii. Networks TF
 - iii. Young Neurobiology TF – highlight work of young neurobiologists
 - iv. ILAE/AES Joint Translational TF – plan to engage

In the coming year, we plan to start the blog posts as detailed above. We will track “hits” and readership interest. We plan to repost the blogs on the ILAE and other websites as appropriate.

Aristea Galanopoulou
Chair, Neurobiology Commission

Pediatrics Commission



Stéphane Auvin

Chair

Stéphane Auvin (France)

Members

Hans Hartmann (Germany)

Jo Wilmshurst (South Africa), Past-Chair

Elissa Yozawitz (USA)

Management Committee Liaison

Helen Cross

The commission's work is mainly organized around the operations of four task forces. **A description of the 2018 activities of the pediatric commission and all related task forces (TFs) is found below.**

The ILAE Pediatrics Commission has been actively involved in the discussion and the work of the Nosology TF for the definition of the epilepsy syndromes (Elissa Yozawitz, Jo Wilmshurst, Stéphane Auvin). The commission has also been interacting with the regulatory affairs TF about the clinical trials in infants (Stéphane Auvin). A common work between the Pediatric Commission and the regulatory affairs TF has resulted in the draft of a new protocol for randomized control trials for focal onset seizure in infants (abstract submitted for the Bangkok IEC 2019 and session proposal submitted for the Geneva ECE, 2020, Stéphane Auvin)

Two publications from the ILAE Pediatric Commission went out during 2018; one from the Comorbidities TF and one from the Research Advocacy TF. These two pieces are the result of the activities initiated during the previous term.

1. Auvin S, Wirrell E, Donald KA, Berl M, Hartmann H, Valente KD, Van Bogaert P, Cross JH, Osawa M, Kanemura H, Aihara M, Guerreiro MM, Samia P, Vinayan KP, Smith ML, Carmant L, Kerr M, Hermann B, Dunn D, Wilmshurst JM. "Systematic review of the screening, diagnosis, and management of ADHD in children with epilepsy". Consensus paper of the

Task Force on Comorbidities of the ILAE Pediatric Commission. *Epilepsia*. 2018;59:1867-1880.

2. Wilmshurst JM, Guekht A, Secco M, Helen Cross J, Perucca E; Advocacy Task Force, Commission of Pediatrics, International League Against Epilepsy. "Advocacy for children with epilepsy: Leveraging the WHA resolution". Advocacy Task Force, Commission of Pediatrics, International League Against Epilepsy. *Epilepsia Open*. 2018;3:167-174.

The Task Force Reports follow.

Neonatal Seizure Task Force (Co-Chairs: Ronit Pressler & Hans Hartmann)

The ILAE's Pediatric Commission set up a TF to update the guidelines on neonatal seizures, which were published jointly by the WHO and the ILAE in 2012. Seizures affect at least 2/1000 neonates. They often are signs of a severe acute health problem, and significantly contribute to morbidity and mortality of both term and preterm neonates. As of today, only very few high-quality studies have addressed optimal diagnosis and treatment of neonatal seizures.

Having finished the literature search, the TF organized a workshop at the 2018 European Epilepsy Congress, aiming to kick off a critical appraisal of the evidence. This workshop was followed by an open meeting bringing together pediatricians, epileptologists, and neonatologists. Prof Linda de Vries from Utrecht (NL) gave an overview on the management of neonatal seizures, highlighting the need for international guidelines. This was followed by Prof Jo Wilmshurst from Cape Town (SA) talking about the principles of guideline development and specific considerations for neonatal seizures. Dr Ronit Pressler from London (UK) and Dr Hans Hartmann from Hannover (GER) gave an update on the current guideline development. The need for further research in the field was further highlighted by case presentations and discussions given by

Prof Martha Feucht from Vienna (AUT) and Prof Stéphane Auvin from Paris (FRA).

Work on the evidence profiles continues and following completion of the systematic literature review; the taskforce aims to draft the guidelines in 2019.

Medical Therapy Task Force (Chair: Lieven Lagae)

The major aim of the Medical Therapy Task Force is to publish at least one paper with a view on current treatment options in young children (< 4 years old), based on (1) available literature data and (2) on current practice. It is clear that there is little literature and that most treatments are prescribed off-label. We will work with typical case scenarios illustrating some common situations in young children presenting with epilepsy. For all scenarios, we will try to identify first, second, and third line (medical) treatment options, covering both first line treatments and treatment options when the child becomes drug-resistant.

During 2018, we identified the following scenarios: 1. A 14 month old child with recurrent typical febrile seizures; 2. A six month old child with typical epileptic spasms; 3. An 18 month child with Dravet syndrome ('epileptic encephalopathy'); 4. A two year old child with tuberous sclerosis (structural epilepsy, cortical 'dysplasia'); 5. A nine month old child with cerebral palsy after hypoxic ischemic encephalopathy (lesional epilepsy).

The ongoing work consists of two processes: 1. Literature review, based on RCT and large case series, for the epilepsy treatments in these five scenarios. 2. Survey amongst pediatric neurologists/epileptologists (based on real life clinical stories) (Ongoing in 2019). A survey will be sent to pediatric epileptologists on all continents with specific questions concerning their first line treatment in these five scenarios. Also, we will ask what second and third line options are in these specific situations.

Research Advocacy Task Force (Chair: Pauline Samia)

The research advocacy TF members remained in regular email contact during 2018, with discussions regarding the most impactful contribution the group could potentially make during its term. A task force meeting was held in August 2018 during the Vienna ECE, then again in November 2018 on the sidelines of the ICNC in Mumbai. The conclusion of these meetings was that the task force would conduct a systematic review on research in the epilepsy field in Africa with a particular focus on the trends in research related to the clinical features, comorbidities, and management of Epilepsy in Children in Sub-Saharan Africa.

The group aims at completing the proposal before March 2019 in compliance with PROSPERO and PRISMA guidelines. Descriptions of etiology shall follow those outlined by ILAE. The team intends to search databases including Medline; Embase; Global Health and CAB abstract databases, and the World Health Organization Library database (WHOLIS) to identify publications. The aim of this research project is to provide a publication that delineates the current state of epilepsy research in Africa and to identify gaps that should be addressed by future research in the region, and to understand the barriers to moving research forward in the region. It is also envisaged that findings from this study would support advocacy efforts to promote epilepsy research in this area.

The task force is planning a PET1 course for health care workers on the sidelines of the fourth African Epilepsy congress in Kampala Uganda in August 2019. Task force members are also planning a research workshop targeting young researchers to encourage more publications from the region by enhancing knowledge and providing mentorship.

Joint Task Force with the Psychiatric commission (Co-Chairs: Kette Valente and Colin Reily)

The Task Force on Psychiatric Issues on Pediatric Epilepsy represents a liaison between the Psychiatry Commission (Mike Kerr) and the Pediatric Commission (Stéphane Auvin).

Pediatrics Commission *(continued)*

During an eight-hour meeting held in Vienna, the task force developed two proposals, as detailed below:

1. A consensus statement on the clinical assessment and treatment of neuropsychiatric conditions in pediatric epilepsy. This work is ongoing and with the support of the Guideline Task Force of the ILAE (process to be initiated the first month of 2019).

2. A Clinical Practice Guideline (CPG) for the diagnosis and treatment of psychogenic non-epileptic seizures in children. This work is ongoing with the final status of the methodology being discussed with the Guideline Task Force of the ILAE (submitted to the ILAE Guidelines TF).

Stéphane Auvin
Chair, Pediatrics Commission

Psychiatry Commission



Mike Kerr

Chair

Mike Kerr (UK)

Members

Rod Duncan (New Zealand)

Kousuke Kanemoto (Japan), Past-Chair

Kette D. Valente (Brazil), Treasurer

Management Committee Liaison

Alla Guekht (Russia)

The goal of the Commission on Psychiatry is to improve the psychiatric health and well being of people with epilepsy through delivering guidance and education to clinicians in the field of epilepsy across the breadth of mental ill health.

Meetings

The commission, including task force leads, met at the 14th European Congress on Epilepsy in Vienna, June 2018.

The meeting focused on:

- Update on establishment of task forces
- Any ongoing liaison issues with the Executive Committee
- Feedback from task forces on work plans and deliverables
- Discussion of budget for 2019

A meeting of the *Pediatric Task Force* was held in Vienna, June 2018. This meeting focused on establishing proposals and a workplan for the two key outcomes of the task force, which will be detailed below.

A meeting of the *Intellectual Disability Task Force* was held in Vienna, June 2018. This meeting focused on developing a workplan for the task force.

Future meetings

The commission submitted several proposals for sessions during the 33rd International Epilepsy Congress in Bangkok, June 2019. The following two were accepted with some modification:

Key Neuropsychiatric Issues in Epilepsy in a Neurological Clinical Setting

Chairs: Mike Kerr (UK) and Kousuke Kanemoto (Japan)

- Clinical Assessment of the Key Psychiatric Comorbidities in Adults with Epilepsy - Mike Kerr (UK)
- Clinical Assessment of the Key Psychiatric Comorbidities in Children with Epilepsy – Kette Valente (Brazil)
- Suicide in Epilepsy - From ideation to planning - How can a neurologist address and help to prevent? – Jakob Christensen (Denmark)
- Treating Psychiatric Disorders in People with Epilepsy: What do we really know? - Kousuke Kanemoto (Japan)

Childhood comorbidities from mechanism to management

Chairs: Kette Valente and Chahnez Triki (Tunisia)

- Epilepsy and autism – Takao Takahashi (Japan)
- Impulse control – Dana Craiu (Romania)
- Cognitive impairment – Lieven Lagae (Belgium)
- Mood disorders – Edward Kija (Tanzania)

During the meeting of the Commission of Psychiatry, held in Vienna, a liaison was established with the Medical Therapies Commission Psychotherapy Task Force (Chair: Rosa Michaelis) and a common forum addressing neuropsychiatric issues was submitted to Bangkok.

Psychiatry Commission *(continued)*

Budget

The commission kept within budget for the year 2018-2019.

Task Force progress

The *Task Force on Identification Treatment and Prevention*, chaired by Marco Mula, has developed a protocol for the development of a consensus document and clinical practice statements for the treatment of depression in adults with epilepsy. The task force had a preliminary meeting in New Orleans to set methodology and allocate specific tasks among task force members. A draft document will be produced after a formal meeting in Baltimore in Dec 2019.

The *Intellectual Disability Task Force*, chaired by Christian Brandt, is in the process of developing further work on a consensus paper on the use of rescue medication in people with an intellectual disability.

The *Psychogenic Nonepileptic Seizure Task Force*, chaired by Markus Reuber, will initially complete a project previously conceptualized, consisting of a global survey of diagnostic video-EEG practices when PNES are a diagnostic possibility (focusing specifically on suggestion/provocation techniques). The results of this survey should form the basis of an ILAE proposal for best video-EEG practices. The task force will also revisit the nosology and definition of PNES. It is hoped that patients all over the world would be likely to benefit if a single diagnostic label was used for their problem internationally and across medical specialties.

The *Task Force on Paediatric Psychiatric Issues*, Chaired by Kette Valente and Colin Reilly, represents a liaison between the joint task force of the Psychiatry and the Pediatric Commission.

The task force has developed proposals on two work plans:

- A consensus statement on the clinical assessment and treatment of common neuropsychiatric conditions in pediatric epilepsy. This work is ongoing and with the support of the Guideline Task Force of the ILAE.
- Clinical Practice Guideline (CPG) for the assessment, diagnosis, and treatment of psychogenic seizures in children. This work is ongoing with the final status of the methodology being discussed with the Guideline Task Force of the ILAE.

Summary

The year 2018-2019 has led to:

1. The development of a workplan from the commission focusing on standards and guidelines by the task forces
2. The establishment of two liaisons with the Pediatric Commission and the Psychotherapy Task Force
3. Contribution to the scientific program of the ILAE Congress in Bangkok

Mike Kerr
Chair, Psychiatry Commission

Surgical Therapies Commission



Lara Jehi

Chair

Lara Jehi (USA)

Core Commission Attendees

Guoming Luan (China)

Karl Rössler (Germany)

Bertil Rydenhaag (Sweden)

Management Committee Liaison

Sam Wiebe (Canada)

Taskforce Chairs and Commission Members

Dario Englot (USA)

Dan Friedman (USA)

Bill Gaillard (USA)

Nathalie Jetté (Canada)

Andrew McAvoy (UK)

Andre Palmi (Brazil)

Felix Rosenow (Germany)

Stephan Schuele (USA)

Howard Weiner (USA)

The commission met in person at AES in December 2018 and reviewed progress made last year. Overall, it was felt that a re-structuring of the commission is necessary to catalyze a more efficient performance. The group decided on a re-organization of the commission around specific projects that would be conceived within the current task forces, but involve interested and committed members from across the commission. This will make tasks more specific and deliverables more reachable.

Each task force's progress was reviewed:

♦ Task Force on Resource-Poor Countries:

a) No projects have been initiated. Options for initiatives were discussed:

1. Various forms of training of individuals from resource-poor regions. This may be achieved by developing a standardized set of educational materials, free access, and made available to physicians from regions where epilepsy education is

needed but funding to travel to traditional courses and fellowships is scarce.

2. Traditional training opportunities are available and used in isolated efforts now to build capacity in resource-poor countries. Identifying these opportunities and advertising them in a more systematic way may increase awareness and use. An inventory or listing of available funded "observer ships" or training fellowships could be developed and posted on the commission's website.
3. A publication on appropriate work-up of patients with different levels of epilepsy surgery case complexity was discussed. A team of interested individuals to write such a paper is needed. Coordination with a similar ongoing effort in the Pediatric Commission will be needed.
4. It was noted that several of the above points align well with the Education Taskforce roles within the commission.

b) Next steps:

1. Some task force members interested in pursuing these opportunities (mainly b and c) have initiated some online discussions. These discussions are encouraged to continue.
2. Members (from this task force or other task forces within the ST Commission) interested in working on projects 2 or 3 should reach out directly to Lara Jehi. If enough interest exists, a serial zoom conference call will be organized to build further.

♦ Taskforce on outcomes:

a) Three projects were discussed:

1. A web-based survey of epilepsy surgery centers to assess current "standard of care" in collection and reporting of outcome measures after epilepsy surgery. The goal is to characterize

Surgical Therapies Commission *(continued)*

current practices, identify areas of alignment and discrepancy, and inform future practices regarding opportunities for improvement. This project is now just an idea. People interested in exploring it further can reach out to Lara.

2. Development of a patient reported memory outcome measure. The MAC-S is a 49-item validated patient reported memory scale that has already been administered to >500 patients in context of formal neuro-psych testing. Robyn Busch and Kristina Malmgren are leading efforts to develop a shorter version. Centers interested in collaborating to validate a shorter version can reach out directly to Lara, Robyn, or Kristina. Related projects would include studying this in context of the Epilepsy Surgery Satisfaction Score.
3. Propensity Score-based comparison of SEEG and SDE. An initial analysis was performed in Cleveland Clinic on 408 patients. Expanding cohort (and depth of variables collected) will increase impact, particularly that comparing two methods in context of a RCT, is unlikely. Centers interested in collaborating on this can reach out to Lara.

✦ Task Force on Pediatric Surgery:

- a) Development of a scale that assesses surgical outcomes beyond seizure freedom. Andre Palmini and Eliseu Paglioli have started with the Porto Alegre Seizure Impact Scale that includes objective and subjective questions. Next steps:

- ✦ Review of the literature to evaluate existing scales of seizure outcome measurements
- ✦ Follow-up conversations on PASIS development and validation
- ✦ Contact person: Andre Palmini

- b) A pediatric surgery meeting to be organized in parallel with the regional ILAE meeting in Latin America.

✦ Taskforce on Education:

- a) Development of epilepsy surgery education curriculum in coordination with the education commission. This was felt to be a critical effort to facilitate spread of information across all ILAE constituencies. Various venues were explored, including online videos and standardized courses.

✦ Taskforce on Evidence Based Practice:

- a) A systematic review of the three most common neuromodulation procedures for epilepsy: We will perform a systematic review of responsive neurostimulation (RNS), deep brain stimulation (DBS) of the anterior thalamic nucleus, and vagus nerve stimulation (VNS). To avoid redundancy with previous reviews on this topic, this systematic review will be focused in its scope and the goal will be to clarify the clinical situations in which the three therapies have been evaluated, and determine where the evidence gaps are. The review will be limited to randomized-controlled trials, plus only those long-term observations studies which followed the RCT patients after the blinded phase. While we know data is insufficient to directly compare one therapy to another, certain general statements can be made regarding the different scopes of the therapies, which may guide decision making in centers and countries where some or all of these therapies are available, and clarify needs for future studies.

- b) Evaluating the incremental value of presurgical diagnostic tests. While this was initially planned as a systematic review, it was determined this would be redundant with comprehensive systematic reviews currently being reported by E-PILEPSY on these topics. It was discussed that, to make further progress in addressing these questions, data sharing between our centers will likely be valuable in the future, after the immediately planned projects are completed.

Lara Jehi
Chair, Surgical Therapies Commission

Young Epilepsy Section



Marian Galovic

Chair

Marian Galovic (UK)

Members

Christos Lisgaras (Greece), Vice-Chair
Genevieve Rayner (Australia), Secretary
Katja Kobow (Germany), Treasurer
Rosa Michaelis (Germany)

Regional Representatives

Musa Mamman Watile (Nigeria), Africa
Mohmad Farooq Shaikh (Malaysia), Asia & Oceania
Caroline Neuray (Austria), Europe
Johann Sebastian Ortiz de la Rosa (Colombia), Latin America
Taylor Abel (USA), North America

YES Task Forces:

Advocacy and Diversity: Rodolfo Cesar Callejas (Mexico) and Musa Mamman Watile (Africa)
Communications: Neha Kaul (Australia)
Education and Career Development: Christoph Schöne-Bake (Germany)

Finances and Conferences: Caroline Neuray (Austria)
Research and Translational: Christos Lisgaras (Greece)
Young Epilepsy Section (YES) members have initiated collaborations with the ILAE Wikipedia Epilepsy Initiative and the Young Neurobiologists Task Force (NBC), focusing on basic science advocacy and the Research Advocacy and Priorities Task Force (TF).

Activities

The ILAE Next Generation Task Force identified the need to better foster the involvement of young people in epileptology and epilepsy research. Following the work of a small organizing committee, the ILAE Young Epilepsy Section (YES) was formally established on May 13, 2018 at a Kick-Off Workshop in London, UK. Fifty-five workshop participants with diverse regional and professional backgrounds discussed and determined the goals and the

organisational structure of an ILAE section to involve and represent young epileptologists. The YES Terms of Reference were approved at this meeting and later endorsed by the ILAE Executive Committee.

The central aims of YES are to (i) attract young people to epileptology and epilepsy research, (ii) foster their professional development, (iii) offer educational and conference activities specific to young participants, and (iv) represent junior members of the ILAE within the organisation. The internal framework of YES was determined at the first YES general assembly meeting on May 13, 2018 and representatives were elected.

Internal communication and diversity:



Channels for international communication were established on the Slack platform. We currently operate 28 channels and our 324 registered contributors (as of January 2019) posted more than 7,000 messages. An online registration form to become an active contributor to YES was set up on our website www.ilae.org/yes. We publish a regular YES newsletter that has more than 500 subscribers as of January 2019.

An important goal for YES is to foster a balanced but diverse global representation of our active members. Regional representatives have organised meetings at regional ILAE conferences and have started to approach national liaisons for each country in their region.

External communication:

The first steps for an efficient external communication were designing a recognisable ILAE-YES logo, securing an online presence on social media (Twitter: @yesILAE; Facebook: /yesILAE) and a website (www.ilae.org/yes). YES members have been supporting the ILAE on social media and have been involved in translating online messaging into Spanish, Portuguese, French, and German.

Young Epilepsy Section *(continued)*

The ILAE Communications & Social Media Task Force identified the benefits of including tech-savvy junior members in their work and invited YES to collaborate on an infographics project. This initiative translates key points of ILAE guidelines and position papers into graphical abstracts. Five infographics have been produced by YES members as of January 2019, which have reached more than 5,000 views on social media.

Education and career development

A Peer2Peer Mentoring programme has been set-up and will debut at the International Epilepsy Congress (IEC) in 2019. This programme will focus on junior and first-time conference participants, who will be mentored by more experienced peers. It will run in parallel with the established ILAE Mentor-Mentee programme that targets more experienced mentees. YES has also put forward plans to establish a Career-Development programme at the IEC 2019 that will include several interactive sessions.

YES members have been involved in shaping the epilepsy curriculum of the ILAE Education task force. Our members will contribute cases into the case-based curriculum. Conferences

YES has had a strong presence at the Latin American and European epilepsy congresses in 2018. We operated booths in the exhibition areas, hosted career-development sessions, and held Q&A sessions about YES. Networking events brought together more than 200 young conference participants in an informal setting. An 'epilepsy run' with 50 participants in the Vienna Prater aimed to increase public awareness about epilepsy.

YES was also represented with various activities at several national conferences, including the annual scientific meetings of the American Epilepsy Society and Epilepsy Society of Australia.

Research and translational aspects

In collaboration with the Young Neurobiologists Task Force of the Neurobiology Commission, YES hosted a successful brainstorming session on "Biomarkers of Epilepsy and Epileptogenesis" and a forum entitled, "Your First Epilepsy Research Project," at the European Conference on Epileptology 2018. A well-attended career funding session on "How to Land an NIH Fellowship or Career Development Award" was also organised during the AES 2018 meeting in New Orleans. The research initiatives targeting young conference participants will be expanded in the future, including several brainstorming sessions and an ILAE-YES Best Presenter Award. Work has begun on a database of epilepsy courses and fellowship opportunities to foster the professional development of early-career clinicians and researchers.

Marian Galovic
Chair, Young Epilepsy Section

Chapters

ILAE has 118 chapters plus one chapter with provisional status to be approved at the General Assembly during the 2019 International Epilepsy Congress in Bangkok, Thailand.

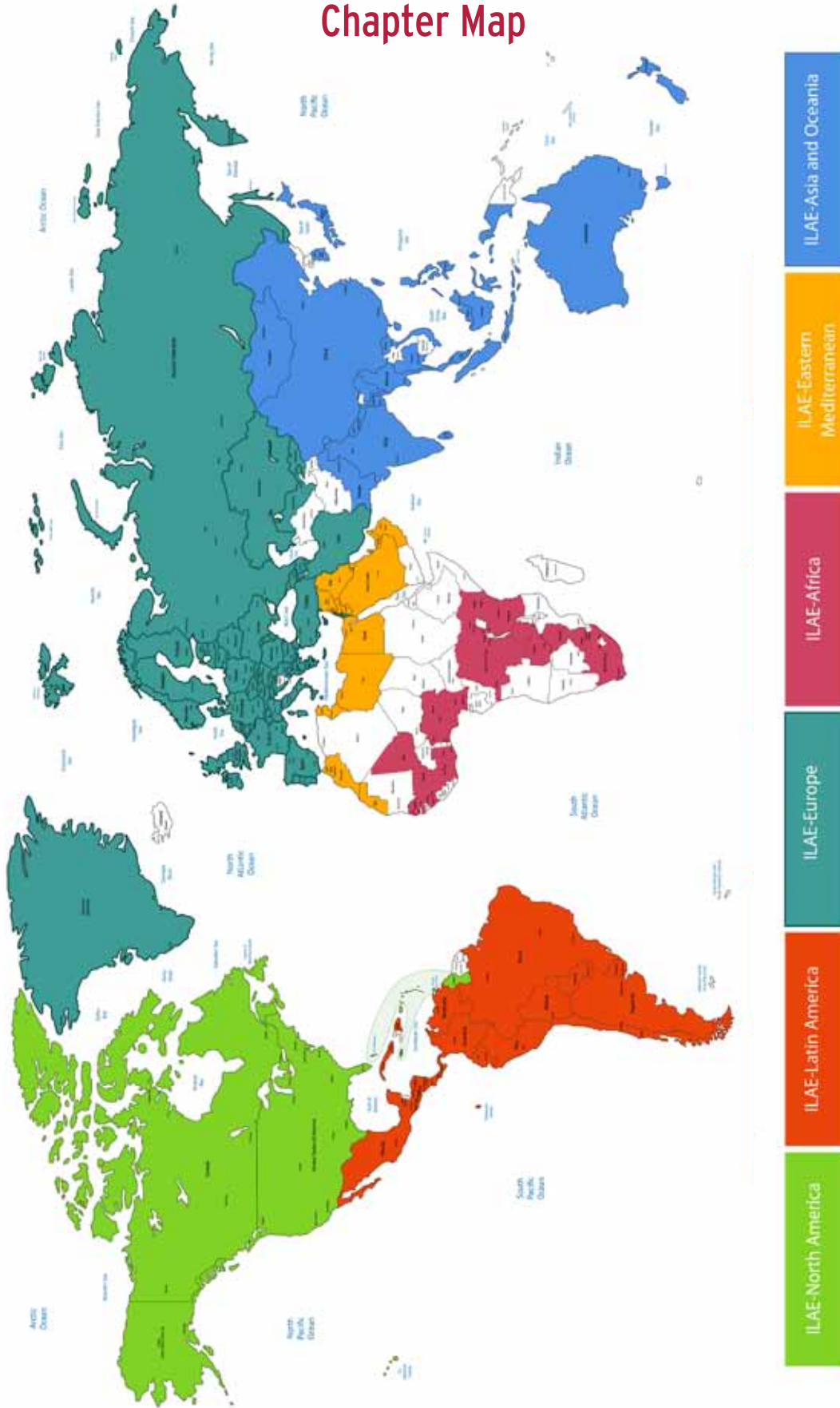
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Chile
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Democratic Republic of Congo
Denmark
Dominican Republic
Ecuador
Egypt
El Salvador
Estonia
Finland
France
Georgia
Germany
Ghana
Greece
Guatemala
Guinea
Honduras
Hong Kong

Hungary
India
Indonesia
Iran
Iraq
Ireland
Israel
Italy
Ivory Coast
Japan
Jordan
Kazakhstan
Kenya
Kosovo
Kuwait
Kyrgyzstan
Latvia
Lebanon
Libya
Lithuania
Malaysia
Mali
Malta
Mexico
Moldova
Mongolia
Morocco
Myanmar
Nepal
Netherlands
New Zealand
Nicaragua
Nigeria
North Macedonia
Norway
Oman
Pakistan
Palestine
Panama
Paraguay
Peru
Philippines

Poland
Portugal
Qatar
Romania
Russia
Rwanda
Saudi Arabia
Senegal
Serbia and Montenegro
Singapore
Slovakia
Slovenia
South Africa
South Korea
Spain
Sri Lanka
Sweden
Switzerland
Syria
Taiwan
Tanzania
Thailand
Tunisia
Turkey
Uganda
Ukraine
United Arab Emirates
United Kingdom
United States of America
Uruguay
Uzbekistan
Venezuela
Vietnam
Zambia (provisional status)
Zimbabwe

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

Chapter Map



Chapter Reports

Chapter reports are listed in order by country.

ARGENTINA: Argentinian League Against Epilepsy

Report By: Damian Consalvo (President)

Publications: None

Summary of Activities:

ARGENTINEAN EPILEPSY CONGRESS 2018

Dr. Samuel Wiebe, president of the ILAE (CAN), Dr. Orrin Devinsky (Online presentation) (USA) and Dr Christian Bien (GER) were the guest to our annual congress. Dr. Santiago Galicchio, past-President of the Argentinian League Against Epilepsy (LACE), was our local guest. The congress had 380 participants from all over the country. Dr Samuel Wiebe was designed as Honorary Member of LACE due to his contribution in the Epilepsy field.

A special tribute for the death of Dr. Natalio Fejerman was held by the President of the Local League, Dr. Damián Consalvo.

Natalio was a neuropediatrician and epileptologist, pioneer in Argentina, Latin America and the world. He was president of LACE and ILAE vice president. He was an extraordinary mentor, he was a great teacher of generations of neurologists and medical students. As part of this tribute, the Scholarship for young epileptologist for a trip to the American Epilepsy Society Meeting was given the name of "Dr. Natalio Fejerman", to the best work presented. The juries were Dr. Santiago Galicchio, Dr. Alfredo Thomson and Dr. Roberto Caraballo, and the winners Dr. Carla Chicco and Dr. Andrés Guzmán.

ARGENTINEAN EPILEPSY CONGRESS 2017

Dr. Helen Cross (UK), Dr. Andrés Kanner (USA) were the guest to our local meeting. Doctors Dileep Nair, Patrick Chauvel, Juan Bulacio and Jorge González Martínez were participants of a special course of Epilepsy Surgery. Dr. Silvia Kochen was our local guest. A special tribute was made by Dr Santiago Galicchio, president of LACE at this moment, to Dr Ricardo Cersósimo for his contribution in the development of pediatric epilepsy in Argentina. The Scholarship to the best work, for a young epileptologist was established for a first time, and the prize was a trip to the American Epilepsy Society Meeting. The juries were

Dr. Verónica Campanille, Dr. Alfredo Thomson and Dr. Roberto Caraballo, and the winner was Dr. Eliana Garino.

LACE MEETINGS INSIDE THE COUNTRY

In the last few years different cities inside the country hosted meetings organized by LACE. Salta, Córdoba, Rosario, Mendoza, Neuquén and Tucumán were the elected cities. The idea of this kind of meetings is to reach doctors inside the country in order to improve training in the field of epilepsy and to discuss difficult cases with the experts. The last meeting was held in Tucumán, with the presence of more than 60 attendees.

OTHER ACTIVITIES

LACE has also contributed to support the National Epilepsy Law (25404), to achieve compliance with it. This law helps epilepsy patients to have access to diagnostic and treatment procedures for their disease. The list of members has been refined and new members were added. We added new benefits too: access to the journals Epilepsy and Epileptic Disorders, for the LACE members.

Web page and social networks

There has been a continuous updating of the website and has maintained a fluid contact by mail with the LACE members. It has also become efficient dissemination of the ILAE activities on the web page. LACE finally landed on the social networks, having great acceptance and dissemination of the activities and information.

Epilepsy week:

As every year in September, in conjunction with Neurological Argentinean Society, the Week of Epilepsy is celebrated, with talks in different entities (In Buenos Aires city and in the rest of the country), aimed at reaching the community.

Challenges:

Be more in contact with people for the government, trying to improve the patients access to specialized medical care, diagnostic studies and treatment of the disease.

Future Plans:

NEXT ARGENTINEAN EPILEPSY CONGRESS 2019
Our next meeting will be in Buenos Aires City, on September 19 and 20. It is confirmed the presence of Dr. Rubén Kuzniecky (USA). Dr. Jacqueline French (USA) Will

Chapter Reports *(continued)*

be our guest too, by an online presentation. Admission to the event is free of charge for the LACE members. The next meeting inside the country will be in May, in Mendoza. Dr iscia Lopez-Cendes will be our guest. LACE is organizing the first online basic course of epilepsy, for young doctors, free of charge for LACE members.

Officer Election Date: Will be at the end of our local Congress September 2019.

AUSTRALIA: Epilepsy Society of Australia

Report By: Patrick Carney (Secretary), Dean Jones (Treasurer) and Terry O'Brien (President).

Publications:

- ✦ Newsletters to Members
- ✦ Valproate Position Statement
- ✦ CBD position Statement

Summary of Activities:

- ✦ Annual Scientific Meeting held October 31 to November 2.
- ✦ Annual Epilepsy Training Day held February 9
- ✦ Annual EEG teaching Course held February 10 – 11
- ✦ Financial Support for the Australian Pregnancy Registry
- ✦ Australian Epilepsy Clinical Trials network established and growing: 12 currently active trials, many in early phase. 5 completed phase. Active collaboration with international clinical trial networks, including the Epilepsy Consortium.
- ✦ Engagement with state based drivers licensing authorities to emphasize neurologist's role in providing relevant information regarding driving fitness, allowing DLAs to use algorithm to determine fitness in most cases
- ✦ Provision of financial support and scholarships for Australian and Asia-Pacific trainees and neurologists.
- ✦ Engagement with teaching and skills development in South East Asian countries
- ✦ Development of a position statement and engagement with government on use of Cannabis derivatives in the management of Epilepsy.
- ✦ Successful push to include vagus nerve stimulation therapy as a reimbursed procedure in Australia.

Challenges:

- ✦ Engagement with government regarding the recognition of patients with epilepsy in the National Disability Insurance Scheme.
- ✦ Delivering high class education and professional meetings in an environment with diminishing resources and pharma support.

Future Plans:

- ✦ Continued development of central purpose of supporting education and scientific understanding of epilepsy.
- ✦ Support of younger members and trainees within the epilepsy community including the promotion of YES, Epilepsy Training Fellowships, and Scholarships for Epilepsy Conference attendances.
- ✦ Develop an Epilepsy pod cast series
- ✦ Growth of clinical trials of new epilepsy therapies

Officer Election Date: Current executive elected November 1, 2018. Next election November 2021.

AUSTRIA: Austrian Society for Epileptology

Report By: Edda Haberlandt (Chairman)

Publications:

Joint publication together with ÖGN (Austrian Society for Neurology) concerning new developments in epilepsy published an epilepsy day in february

Summary of Activities:

Conferences:

- ✦ "Dreiländertagung" 3.-6.5.2017 Vienna Austria, 1.024 participants
- ✦ "DACH-Tagung" 12. – 14.10.2017, Prien am Chiemsee, Germany
- ✦ "Jahrestagung des Deutsch-Österreichisch-Schweizer Arbeitskreises Epilepsie", 11.-13. Oktober 2018, Congress Wolfgangsee/ St. Wolfgang, Austria
- ✦ 13th European Congress on Epileptology (26.-30. August 2018), Vienna Austria

Chapter Reports *(continued)*

Board Meetings

- ✦ 2017: 02.02.2017, 03.05.2017, 03.10.2017, 24.11.2017
- ✦ 2018: 19.04.2018, 29.08.2018, 15.11.2018

Endorsements:

- ✦ Forschungsstipendium 2017 für Dr. Alexandra Rohrer
- ✦ Forschungstipendium 2018 für Dr. Martin Krenn
- ✦ Ernst Niedermeyer Prize 2017
- ✦ Dr. Claudia Granbichler mit 19 Punkten: Potential years lost and life expectancy in adults with newly diagnosed epilepsy
- ✦ Herbert Reisner Prize 2018
- ✦ Jury: Haberlandt, Unterberger, Luef, Trink
- ✦ Dr. Karin Trimmel: Left temporal lobe language network connectivity in temporal lobe epilepsy

Challenges:

Motivation of more members to participate in the management board

Future Plans:

"Journal of Clinical Epileptologie" - joint journal of DGfE, ÖGfE, DGfE and Swiss league against epilepsy

Officer Election Date: November 2020

azerbaijan: Azerbaijan League Against Epilepsy

Report By: President Professor Sharif Magalov, Secretary General Dr. Shahla Melikova

Publications:

59 articles on topics related to epilepsy were published in 2017-2018

Summary of Activities:

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

Challenges:

Educational Activities include Schools on Epilepsy for patients with epilepsy and their relatives.

Future Plans:

Continuation of the 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 tumor-related epilepsy), epilepsy in children, epilepsy in cerebral palsy, neonatal seizures.

Officer Election Date: June 2018

belgium: Belgian League Against Epilepsy

Report By: Emma Staut

Publications:

- ✦ A new brochure about the driving restrictions
- ✦ A new brochure for children (<https://ligueepilepsie.be/Enfants-epilepsie-et-activites-sportives-132.html>)

Summary of Activities:

- ✦ "Epilepsy doesn't put me offside" - a national awareness campaign in Belgium with RSC Anderlecht.
- ✦ Patient Education
- ✦ The start of group insurance for people with epilepsy
- ✦ Music for Life

Future Plans:

- ✦ National Epilepsy Day in February
- ✦ EEG course
- ✦ An online awareness campaign about the myths
- ✦ Cooperation with the public transport in Belgium

Officer Election Date: n/a

Chapter Reports *(continued)*

BULGARIA: Bulgarian Association Against Epilepsy

Report By: Petia S. Dimova

Summary of Activities:

One day Epilepsy course during the bi-annual Child Neurology Conference, October 2018 with chapter meeting

Challenges:

Too many - especially liaisons to government, parliament etc.

Future Plans:

To apply for next East-European Epilepsy Course (2020)

Officer Election Date: November 2015; next - November 2019

CAMEROON: Cameroonian League Against Epilepsy

Report By: Pr Callixte KUATE TEGUEU, Secretary General

Summary of Activities:

Public Outreach:

From February 1-8, 2018, sensitization campaigns were organized in many TV and Radio in Douala, economic capital of Cameroon. We had many interviews from Canal 2 International, Equinoxe TV and Radio, Cameroon Radio and Television, Penamundi FM. The message of the Cameroonian League was focused on the causes of epilepsy, sign and symptoms, fight against stigma and treatment modalities. The following days, our outpatient consultations were full of patients with epilepsy, some coming from 600 km away from Douala after seeing on TV that epilepsy can be treated.

Training 1:

A scientific conference was organised on February 8, 2019 at The Conference hall of the Laquintinie Hospital Douala, chaired by the Director of the Hospital Pr Louis Richard NJOCK. Almost 189 practitioners attended the meeting (70% General Practitioners, medical students, neurologist, Internal Medicine specialist, etc.). Many subjects were

discussed, including epilepsy definition, epidemiology in Cameroon, videos of seizures, paraclinical investigations, treatment and new concepts in epilepsy. We had a great support from pharmaceutical industries like SANOFI and NOVARTIS.

Training 2:

As part of our usual collaboration, the Ministry of Public Health has asked us to train the health staff of some health districts of the Center and Adamawa Regions of Cameroon. In May and June 2018, members of the Cameroonian League successfully trained more than 100 health personnel on the diagnosis and care for people with epilepsy at Bafia, Ndikinimeki, Makenene, Ebebda, Monatele, Ntui, and Ngaoundéré rural health districts.

Challenges:

- Regular stockouts of antiepileptic drugs, mainly Phenobarbital, Clobazam and Clonazepam
- High cost of antiepileptic drugs in Cameroon with very few generic drugs
- More sensitization campaign in rural areas of the country
- Training of health personnel on the diagnosis and treatment of epilepsy in rural areas.

Future Plans:

- Celebrate the 2019 World Epilepsy day in February 2019,
- Organize a General Assembly meeting and election of new executive of the League.

Officer Election Date: February 8, 2019

CANADA: Canadian League Against Epilepsy

Report By: CLAE

Publications:

CLAE Connections – our league newsletter – of which 6 were published in 2017 and 2018. 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.

Chapter Reports *(continued)*

Summary of Activities:

Scientific and Educational Meeting:

Both the 2017 and 2018 Scientific Meetings were a great success. Topics in 2017 included the following: neuropsychology of epilepsy, newer medical treatments, update on infantile spasms, women and epilepsy, brainstem seizures, and more. At the 2017 conference we presented the Excellence in Research Award.

Topics in 2018 included the following: Brain on Fire: Inflammation and the Childhood Onset Epilepsies, Artificial Intelligence and Epilepsy and Post Traumatic Epileptogenesis: From Bench to Bed, and others. At the 2018 meeting we announced two winners of the Junior Investigator Award.

Summary of Activities in 2017 and 2018

In addition to our newsletter, we completed a major financial audit (no concerns) and funded three epilepsy fellowships awards in 2017 and one in 2018. We awarded our usual trainee/allied health awards for best publications (fellow award, grad student or medical student award, resident award and allied health student award). New in 2018, Canadian fellows were able to apply for the J. Kiffin Penry MiniFellowship Program Award, which was previously only available in the U.S.

In 2017, we held a meeting during the American Epilepsy Society ASM, where we awarded the Wilder Penfield Award, the Junior Investigator Award, and the Clinical Practice/Advocacy Award.

Concerning membership, from July 2016 to July 2017 we had 203 members, and from July 2017 to 2018 we had 193 (the 2018 to 2019 numbers are pending).

Challenges:

Nothing to report.

Future Plans:

The new President, Dang Khoa Nguyen has proposed the following activities in the next two years:

1. Creation of a French committee to establish a policy of the place of French in CLAE activities and help in the translation of documents.
2. Creation of a Women with epilepsy task force, notably to help increase recruitment in the North American Pregnancy Registry.
3. Increase collaboration with North American Regional Commission with the organization of the first North American Regional Epilepsy Meeting in Toronto (2020) and the establishment of a Center-to-Center program between the Epilepsy Society of the Caribbean and the CLAE (starting with The Eric Williams Medical Sciences Hospital in Trinidad Tobago and The University of Montreal Hospital Center in Canada).
4. Improvement on the obtainment of funding to create prizes or small grants named after outstanding CLAE members: a) Origami4epilepsy fundraiser; b) Warren Blume Scientific day and fundraising dinner; c) Marilyn and Jean Gotman Scientific day and fundraising dinner; d) Brain Canada research proposal ("The CLAE epilepsy study").

Officer Election Date: September 20, 2019

CHILE: Chilean League Against Epilepsy

Report by:

Dr Juan Salinas, President; Dr Carla Manterola, General Secretary; Dr Perla David, Director

Summary of Activities

1. Regular Meetings

Taking place the second Saturday of every month during 2017-2018. Due to the increasing number of epilepsy-related symposia held in our country -usually supported by our society, some of the original meetings were rescheduled.

♦ Regular Meeting N° 172

Saturday, March 11th, 2017 "ANNUAL MEETING OF THE CHILEAN SOCIETY OF EPILEPTOLOGY"

Society Board

Chapter Reports *(continued)*

♦ Regular Meeting N° 173

Saturday, April 8th, 2017 “PROTODHERIN 19 AND ITS ROLE IN EPILEPSY”

Dr Cristian Cuitiño

Pediatric Neurology Resident, Dr Luis Calvo Mackenna Hospital

♦ Regular Meeting N° 174

Saturday, May 20th, 2017 “EPILEPSY AND ATTENTION-DEFICIT HYPERACTIVITY DISORDER (ADHD)”

Dr Macarena Bertrán, Pediatric Neurologist, Talca Regional Hospital

♦ XVII WINTER SYMPOSIUM ON EPILEPSY

Friday, June 2nd, and Saturday, 3rd, 2017

“EPILEPSY AS A MARKER OF DISEASE”

International Guest: Dr Jaume Campistol

Pediatric Neurologist, Sant Joan de Déu Hospital, Barcelona, Spain

♦ Regular Meeting N° 175

Saturday, July 8th, 2017

“ETHOSUXIMIDE IN CHILD ABSENCE EPILEPSY WITH ROLANDIC SPIKES”

Dr Álvaro Velásquez

Pediatric Neurologist, Chilean League Against Epilepsy/German Clinic

♦ Regular Meeting N° 176

Saturday, August 19th, 2017

“NATIONAL EPILEPSY PROGRAM – MINISTRY OF HEALTH”

Dr Lilian Cuadra

Pediatric Neurologist, Dr. Alfonso Asenjo Institute of Neurosurgery

♦ Regular Meeting N°177

Saturday, September 9th, 2017

“REVISED CLASSIFICATION OF SEIZURES AND EPILEPSIES”

Dr Johnny Montiel Pediatric Neurologist, Children’s Institute of Health, Lima, Perú

Dr Juan Luis Moya Pediatric Neurologist, Dr Luis Calvo Mackenna Hospital/University of Chile

♦ Regular Meeting N°178

Saturday, October 14th, 2017

“EARLY-ONSET EPILEPTIC ENCEPHALOPATHIES”

Dr Carolina Quintana Pediatric Neurologist
Dr Exequiel González Cortés Hospital

♦ Regular Meeting N° 179

Saturday, November 11th, 2017

“NEW HORIZONS IN THE TREATMENT OF NEURODEGENERATIVE DISEASES: LIPOFUSCINOSIS AS A PARADIGM”

Dr Nicola Specchio

Pediatric Neurologist, Neuroscience Department, Bambino Gesù Children Hospital, Rome, Italy

♦ Regular Meeting N° 180

Saturday, March 17th, 2017

“ANNUAL MEETING OF THE CHILEAN SOCIETY OF EPILEPTOLOGY”

Society Board

♦ Regular Meeting N° 181

Saturday, April 14th, 2018

“EPILEPSY AND GLUT-1 DEFICIENCY”

Dr Patricio Lacaux Uribe

Pediatric Neurologist, San Juan de Dios Hospital

♦ REGULAR MEETING N°182

Saturday, June 9th, 2018

“NONEPILEPTIC PAROXYSMAL EVENTS”

Dr José Ignacio Marín

Pediatric Neurology Resident, Catholic University of Chile

♦ XVIII WINTER SYMPOSIUM ON EPILEPSY

Friday, July 6th, and Saturday, July 7th, 2018

“OLD QUESTIONS, NEW ANSWERS:”

Internacional Guest: Dr Giuseppe Gobbi

Pediatric Neurologist, Institute of Neurologic Sciences, Ospedale Bellaria, Bologna, Italy

♦ Regular Meeting N° 183

Saturday, August 11th, 2018

“PRESURGICAL ASSESSMENT AND INVESTIGATION IN REFRACTORY EPILEPSY”

Dr Reinaldo Uribe San Martín

Chapter Reports *(continued)*

Neurologist, Catholic University of Chile/Dr Sótero Del Río Hospital

♦ Regular Meeting N° 184

Saturday, September 8th, 2018 “SURGICAL TREATMENT OF CAVERNOME-RELATED EPILEPSY” Dr Francisco José Rojas Zalazar
Neurosurgeon, Dr Alfonso Asenjo Institute of Neurosurgery

♦ Regular Meeting N°185

Saturday, October 20th, 2017
“ANTI-NMDA-R ENCEPHALITIS IN PEDIATRIC POPULATION”
Dr Jovanka Pavlov Pediatric Neurologist, Carabineer Hospital/German Clinic/Chilean League Against Epilepsy

2. Congresses, Courses and Symposia

Year 2017

XVII Winter Symposium on Epilepsy

On June 2nd and June 3rd, 2017, the XVI Winter Symposium on Epilepsy was held at the Neruda Hotel (Providencia, Santiago, Chile). Its motto was “Epilepsy as a marker of disease.” It was a pleasure to receive Dr. Jaume Campistol, our special guest from Sant Joan de Déu Hospital (Barcelona, Spain), who shared with us his enormous experience in the field of metabolic disease in children. We also enjoyed diverse conferences by leader local neurologists and neurophysiologists, as well as the presentation of original works from clerks, residents and specialists.

Organizing Committee: Dr. Juan Salinas & Dr. Juan Moya (presidents), Dr. Carla Manterola, Dr. Perla David, Dr. Cayetano Napolitano, Dr. Rubén Darío Ramírez.

XXXV SOPNIA Congress

From November 15th to November 17th, 2017, the XXXV Congress of the Society of Psychiatry and Neurology of Childhood and Adolescence (SOPNIA) was celebrated at the Enjoy Hotel in Puerto Varas (Los Lagos Region, Chile). Our Society had a participation in a tribute session dedicated to honor the legacy of Dr. Marcelo Devilat Barros, notable Child Neurologist and former President of our Society, deceased recently.

LXXII SONEPSYN Congress

From November 9th to November 8th, 2017, the Society of Neurology, Psychiatry and Neurosurgery (SONEPSYN) celebrated its LXXII Congress, taking place at the Enjoy Hotel in the beautiful city of Viña del Mar (Valparaíso Region, Chile). The Congress was supported by our Society and we had the chance to attend interesting exhibitions by distinguished Neurologists and Psychiatrists from overseas.

Year 2018

I International Symposium on Child Neurological

Emergencies (Dávila Clinic, Santa María Clínic)
The 1st International Symposium on Child Neurological Emergencies, organized by Dávila Clinic and Santa María Clínic, took place on April 12th and April 13th, 2018, at the Aula Magna of Los Andes University. Prominent neurologists, including specialists in epilepsy, were part of the academic program. This event was sponsored by our Society.

IX International Symposium on Epilepsy (Las Condes Clinic)

Las Condes Clinic celebrated its 9th International Symposium on epilepsies on May 31st and June 1st, 2018. This year's premise was denominated “Epilepsy: diagnostic and therapeutic controversies”. Expositors from Europe and the United States were invited, and the event was supported by our Society.

XVIII Winter Symposium on Epilepsy

On July 6th and July 7th, 2018, the XVIII Winter Symposium on Epilepsy was held at the Neruda Hotel (Providencia, Santiago, Chile). Its motto was “Old questions, new answers?”. Dr. Giuseppe Gobbi, child neurologist from the Institute of Neurological Sciences at Bologna, Italy, was our special guest speaker. Dr. Gobbi gave us his points of view in the management of infantile spasms and continuous spike-and-wave of sleep (CSWS), aside from being a really nice guest to work with. As usual, we also included diverse conferences by leader local neurologists and neurophysiologists, and the presentation of original works from clerks, residents and specialists.

Organizing Committee: Dr. Claudia Riffo & Dr. Álvaro Velásquez (presidents), Dr. Carla Manterola, Dr. Perla

Chapter Reports *(continued)*

David, Dr. Juan Salinas, Dr. Rubén Darío Ramírez.

X Congreso Latinoamericano de Epilepsia/Latin American Congress on Epilepsy, LACE

The 10th Latin American Congress on Epilepsy (LACE) was celebrated in San José, Costa Rica, from September 29th to October 2nd, 2018. Two of our board members attended the congress (Dr. Juan Luis Moya and Dr. Darío Ramírez). The annual report of our Society was presented by Dr. Alejandro De Marinis (representative of Chilean League against Epilepsy) in the general assembly of Latin American chapters, held on September 27th.

XXXVI SOPNIA Congress

From November 7th to November 9th, 2018, the XXXVI Congress of the Society of Psychiatry and Neurology of Childhood and Adolescence (SOPNIA) was celebrated at the Santa Cruz Plaza Hotel in Santa Cruz City (O'Higgins Region, Chile). This event was sponsored by our Society, and we could enjoy remarkable expositions by renowned speakers, next to one of the biggest vineyard areas in the whole country.

LXXIII SONEPSYN Congress

From November 7th to November 9th, 2017, the Society of Neurology, Psychiatry and Neurosurgery (SONEPSYN) celebrated its LXXIII Congress, taking place at the Enjoy Hotel in Pucón (Araucanía Region, Chile). The Congress was sponsored by our Society and we had the chance to attend interesting exhibitions by distinguished specialists.

Current Challenges in Epilepsy (German Clinic)

German Clinic held its biennial epilepsy symposium, and the chosen motto for the 2018 edition was "Current Challenges in Epilepsy: from the simple ones to the complicated ones". Illustrious specialists from overseas gathered at the Clinic's Aula Magna on November 29th and November 30th. The event was sponsored by our Society.

Continuing Education in Epilepsy 2018

Due to the great number of courses dedicated to epilepsy, with direct participation of our board members, it became difficult to launch our e-learning course this year. We are already planning a well-developed program for 2019, under the name "Semiology in epilepsies."

3. Activities in Relation to the Global Campaign

Celebration of Latin American Day of Epilepsy

We celebrated the Latin American Day of Epilepsy on September 9th, 2018. The Chilean League Against Epilepsy organized a commemorative activity on September 12th, 2018, involving the participation of most institutions that are currently working in epilepsy. Our board participated actively in this meeting and Dr. Juan Luis Moya gave a speech on behalf of the Society, making a call to build bridges between institutions and to join forces together in collaborative groups.

Publications and Academic Activities

Chilean Journal of Epilepsy

The Chilean Journal of Epilepsy is the official publication of our Society. Dr. Juan Luis Moya features as its main editor, taking the place of Dr. Perla David, who developed an incomparable work for several years and resigned her labor as Editor in October 2017. During 2017-2018, we released the 17th and 18th volumes of this Journal, each one composed of three numbers (the 3rd number of the 18th volume is in press currently). Next year we shall release three brand new chapters as part of the 19th volume.

Among the published material, we can mention: original papers, case reports, reviews and updates. We must remark that the journal number corresponding to August 2017 (volume 17, number 2) included publications from notable authors, all of them dedicated to the memory of Dr. Marcelo Devilat Barros, foundational member of our Society, who had passed out in June 2017. It became kind of a special edition, a small but significant tribute to the man who fought bravely for decades, trying to get epilepsy "out of the shadows", and defending fiercely the rights of people with epilepsy and their families. May he rest in peace. Our current official ISSN 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 <http://www.revistachilenadeepilepsia.cl/>.

Continuing Medical Education

Between September and November of the current year, we performed the first version of our Continuing Medical

Chapter Reports *(continued)*

Education (CME) Course, denominated “Updates in Epilepsy”. This course was presented in the e-learning format, and it counted with 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 <http://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 on Epilepsy, Continuing Medical Education)
- 4) Notes (Updates on epilepsy, History of epilepsy)
- 5) News about epilepsy
- 6) Staff and Associates
- 7) Links to ILAE, IBE, WHO and MINSAL; and to the Chilean Journal of Epilepsy
- 8) Contact

The site has played an important role for university students, who are the main users asking for references and information. We also receive frequent requests from patients themselves and their relatives. Under the spirit to expand knowledge about epilepsy in medical fields and among the community, we have collaborated with national diffusion of epilepsy-related topics actively through the website. Some of the presentations from our meetings (including the Winter Symposium on Epilepsy) have been shared at the webpage under prior authorization from its authors, and they can be downloaded free-of-charge

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 current date, and it is available for members at the headquarters of the Society of Epileptology of Chile, in addition to being online. Furthermore, we keep a paperback collection of the eighteen volumes of the Chilean

Journal of Epilepsy, which can also be accessed by our Society members and health professionals in general.

Activities with Local IBE Affiliates

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);
- The Chilean Society of Clinical Neurophysiology (SOCHINEUROFISIOLOGIA); and
- The Association of Leagues against Epilepsy, Chile (ANLICHE).

Members of the board participate in the Epilepsy Regulatory Group of the Ministry of Health of Chile (MINSAL): Dr. Juan Luis Moya, Dr. Rubén Darío Ramírez, Dr. Juan Salinas.

The connections between our Society (Chilean Chapter of ILAE) and the Chilean League against Epilepsy (Chilean Chapter of IBE) have grown strong during the last year, and there are various upcoming projects for our institutions to work together.

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, 2018. The Chilean League Against Epilepsy organized a commemorative activity on September 12th, involving the participation of the majority of institutions that are currently working in epilepsy. Our board participated actively in this meeting and Dr. Juan Luis Moya gave a speech on behalf of the Society, making a call to build bridges between institutions and to join forces together in collaborative groups.

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COLOMBIA: Colombian League Against Epilepsy

Report By: Jean Paul Vergara

Summary of Activities:

2017

1. Reform of League statutes to adapt to Law 1414 of 2010 and to the National Epilepsy Award Foundation Margaret Merz de Fandiño
2. Organization regional chapters. 12 chapters were made in Colombia, with personal trips to each one of them
3. Patient donations, to support the League.
4. Each chapter should have, among its managing members, other professionals than doctors and will have as postulates:
 - a. Human rights of people with epilepsy within the framework Law 1414/10
 - b. Promote the rehabilitation of people with epilepsy and mental development problems, trying to lead this process in the public schools, "Remedial Classrooms" for this 25-30% people with epilepsy and cognitive disorders (unknown in our society) and thus avoid stigma and discrimination.
 - c. Promote research in epilepsy, with the help of the National Epilepsy Prize Foundation Margaret Merz de Fandiño.
5. The regulations and structural organization of LCE were made

2018

In this congress, we'll meet in different commissions like Human Rights, Rehabilitation, Education and Scientific to work in aspects related with each commission. Commission, consisting of neurologists, neurophysiologists, neuropediatricians.

The LCE became the rector of national issues related with epilepsy, such as training neurologists and epileptologists or neurosurgeons with are part of epilepsy groups.

Also, we want to work in operative definition of Epilepsy Center, epilepsy groups, guidelines of epilepsy programs.

1. A new board of directors was elected in the Assembly and two non-medical members were elected. Possession of them took place, delivering all the documents (statutes, regulation)
2. The commission works with the government institution to lookout the care programs dedicated at epilepsy patients.
3. The LCE will work strengthen relations with the government statements to work in special programs dedicated to epilepsy patients.

Challenges:

A new board of directors was elected in the Assembly and two non-medical members were elected. Possession of them took place, delivering all the documents (statutes, regulation)

Future Plans:

SYMPOSIUM OF EPILEPSY 2019

Officer Election Date: 2021

DEMOCRATIC REPUBLIC OF CONGO: Congolese League Against Epilepsy

Report By: Pierre MK Luabeya

Publications:

Neurocysticercosis and Epilepsy in sub-Saharan Africa. Brain Research Bulletin. Athanase Millogo, Alfred Kongnyu Njamnshi, Mesu'a Kabwa Pierre Luabeya, Brain Research Bulletin, 2018

Summary of Activities:

During the year 2018, activities of LICOCE have consisted essentially to continue implementation of our chapter and recruitment of new members across the country. Dozens of new members from the South, Center and East of the country have been registered at LICOCE.

LICOCE continued the work of popularizing epilepsy across the country. These activities were intended to

Chapter Reports *(continued)*

publicize the disease in order to recruit potential members of the National Bureau against Epilepsy. This Bureau is called to work with the LICOCE.

It should also be noted that, under the impetus of LICOCE, several studies on epilepsy have been carried out or are being carried out, by young colleagues from the departments of neurology and psychiatry in different universities of the country.

The LICOCE plans to organize a joint workshop on epilepsy with the African Regional Commission for IBRO. This will be to help people to exchange on the incidence of tropical diseases in our setting. This workshop is planned for November 2019.

Challenges:

See the Report above

Future Plans:

See the report above

Officer Election Date: November 2019

CROATIA: Croatian League Against Epilepsy

Report By: Silvio Basic, President of CLAE

Publications:

Four newsletters and several articles were published in 2017-2018 on topics related to epilepsy. Also, one issue of the journal *Medicus* was devoted to epilepsy topics.

Summary of Activities:

- The main activity during term 2017–2018 was organization of the 13th Croatian Symposium on Epilepsy which took place in Šibenik from September 15-18, 2018. During the Symposium, many outstanding and interesting lectures were held. There have been more than 100 participants and the feedback from the conference was overwhelmingly positive.
- CLAE took place in the organization of the Adriatic Neurology Forum (ANF) 2017. in Opatija (Croatia) and 2018. in Monopoli (Italy). ANF is an important regional meeting where neurologists and

neuropediatricians from our region have opportunity to hear lectures given by the leading world experts.

- CLAE participated at the 46th Symposium of Croatian Child Neurology Society
- CLAE also took place in organization of several workshops on epilepsy
- CLAE participated in activities for Epilepsy Day in Croatia (February 2017 and 2018). The events were organized by CLAE, Croatian Child Neurology Society, Association for Epilepsy and City Hall.
- CLAE members created Croatian „Guidelines for Pharmacological Treatment of Epilepsy” and “Guidelines for Classification and Diagnosis of Epilepsy.” These guidelines will be implemented in Croatian Health Insurance Fund guidelines which will have major impact on neurologists and general practitioners everyday work.
- We started an implementation of a new transitional model for patient with epilepsy from a pediatric care setting to adult care setting.

Challenges:

Our goal is to implement new Croatian guidelines in everyday practice, along with education of general practitioners.

Future Plans:

In cooperation with the Serbian League Against Epilepsy CLAE will organize Migrating Course in Belgrade 2019. CLAE will continue to work closely with the ILAE chapters from neighboring countries. Also, CLAE will continue to promote the development of epileptology in Croatia and participate in education of neurologists, as well as epilepsy nurses. We would like to improve presurgical diagnostic procedures for epilepsy, as well as epilepsy surgery in adults and children with refractory epilepsy.

Officer Election Date: 2020.

CUBA: Cuban League Against Epilepsy

Report By: Lilia Morales Chacon

Chapter Reports *(continued)*

Publications:

- AU: Zaldivar Bermúdez, M; Gómez, L; Grass, D; Morales Chacón, L; Báez, MM; Ortiz, G
- TI: Autoestima, efectividad y funcionamiento urogenital en pacientes con síndrome parkinsoniano
- FU: Revista Electrónica de Psicología de Iztacala 2018; 21(2) [Resumen] [Texto completo]
- INDEX: REDIB, IRESIE, Portal de Revistas Científicas y Arbitradas UNAM
- 1273
- AU: Zaldivar Bermúdez, M; Morales Chacón, LM; Fernández Martínez, E; Quintanal Cordero, NE
- TI: Capacidad de afrontamiento y calidad de vida en pacientes con epilepsia fármaco-resistente tratados con lobectomía temporal
- FU: Revista Rev Cubana Neurol Neurocir. 2018; 8(1)
- AU: Mendieta Pedroso, MD; Bender del Busto, JE; González López, I; Vallejo Ramírez, A
- TI: Mortalidad por enfermedad cerebrovascular en mayores de 60 años en Mayabeque 2011- 2017
- FU: Revista de Ciencias Médicas de Mayabeque, Volumen 25, Número 2 (2018) [Resumen] [Texto completo]
- INDEX: Portal Informed
- 1274
- AU: Bender del Busto, Juan E.
- TI: Trastornos del lenguaje y Epilepsia
- FU: Rev Cubana Neuro Neurocir. 2018 Julio-Dic.; 18(2)
- INDEX: Portal Infomed
- 1278
- AU: Bender del Busto, JE
- TI: La epilepsia, un problema de salud a escala mundial
- FU: Rev haban cienc méd [Internet]. 2018 [citado 21 Nov. 2018];17(4):660-3. Disponible en: <http://www.revhabanera.sld.cu/index.php/rhab/article/view/2491>
- INDEX: SCIELO [Resumen] [Texto completo]
- AU: Suárez-Medina, R; Morales-Chacón, LM; Venero-Fernández, SJ; Liu, C; Fogarty, AW; Neligan, A.
- TI: Epilepsy Mortality Trends in Cuba compared to England and Wales: 1987-2010
- FU: Epilepsy Behav. 2018; 85:72–75 FI: 2,631 [Resumen] [Texto completo]
- INDEX: Scopus, PsycINFO, PubMed, ScienceDirect, Google Scholar
- 1256
- AU: Morales-Chacón, LM; Jiménez-Hinojosa, I; Valdés-Sedeño, R; Santos, A; de la Rosa-Guerra, H; Alfonso-Alfonso, M
- TI: Electroencefalograma cuantitativo en la epilepsia mioclónica juvenil tratada con Lamotrigina y Valproato
- FU: Rev Chil Epil. 2018; 18(1):6-13 [Resumen] [Texto completo]
- INDEX: Scielo
- 1246
- AU: Morales Chacón, LM; Garcia Maeso, I; Báez Martin, MM; Bender del Busto, JE; García Navarro, ME; Quintanal Cordero, N; Estupiñán Díaz, B; Lorigados Pedre, L; Valdés Yerena, R; Gonzalez, J; Garbey Fernandez, R; Sánchez Coroneux, A
- TI: Long-Term Electroclinical and Employment Follow up in Temporal Lobe Epilepsy Surgery. A Cuban Comprehensive Epilepsy Surgery Program
- FU: Behav. Sci. 2018, 8, 19; doi:10.3390/bs8020019 [Resumen] [Texto completo]
- INDEX: PubMed (NLM); Web of Science (Clarivate Analytics); DOAJ - Directory of Open Access Journal; PubMed Central (NLM), entre otros.
- AU: Lorigados Pedre, L; Morales Chacón, LM; Pavón Fuentes, N; Robinson Agramonte, MA; Serrano Sánchez, T; Cruz-Xenes, RM; Díaz Hung, ML; Estupiñán Díaz, B; Báez Martín, MM; Orozco-Suárez, S
- TI: Follow-Up of Peripheral IL-1 β and IL-6 and Relation with Apoptotic Death in Drug-Resistant Temporal Lobe Epilepsy Patients Submitted to Surgery
- FU: Behav. Sci. 2018, 8, 21; doi:10.3390/bs8020021

Chapter Reports *(continued)*

[Resumen] [Texto completo]

- ♦ INDEX: PubMed (NLM); Web of Science (Clarivate Analytics); DOAJ - Directory of Open Access Journal; PubMed Central (NLM), entre otros.
- ♦ 1271
- ♦ AU: Lorigados Pedre, I; Gallardo, JM; Morales Chacón, L; Vega García, A; Flores-Mendoza, M; Neri-Gómez, T; Estupiñán Díaz, B; Cruz-Xenes, RM; Pavón Fuentes, N; Orozco-Suárez, S
- ♦ TI: Oxidative Stress in Patients with Drug Resistant Partial Complex SeizureFU: Behav. Sci. 2018, 8(6), 59 [Resumen] [Texto completo]
- ♦ INDEX: PubMed (NLM); Web of Science (Clarivate Analytics); DOAJ - Directory of Open Access Journal; PubMed Central (NLM), entre otros.

Summary of Activities:

- ♦ Curso Task force Epilepsia en la APS 2018
- ♦ Curso Academia Latinoamericana de epilepsia. Cirugia de las epilepsias.
- ♦ Curso actualización en epilepsia. Utilidad del EEG y Video EEG en las epilepsias. INN. 5 junio 2015
- ♦ Curso- Entrenamiento. "Epilepsias farmacorresistentes: aspectos clínicos y quirúrgicos". UNIVERSIDAD DE CIENCIAS MÉDICAS DE LA HABANA.FACULTAD VICTORIA DE GIRÓN. PLAYA DEPARTAMENTO DE NEUROLOGÍA CLÍNICA. 2 - 30 de noviembre, 2018. 48 horas. Profesor y Coordinador

Challenges:

Congresos Nacionales

Future Plans:

Curso Nacional Epilepsia

Officer Election Date: Noviembre 2019

DOMINICAN REPUBLIC: Dominican Republic League Against Epilepsy

Report By: Diogenes Santos Vilorio

Publications:

Manual for management of Epilepsies

Summary of Activities:

- ♦ Several conferences about Epilepsies and treatment gap for neurologists, internists and pediatrics.
- ♦ Held monthly conference discussions about the most important articles published in *Epilepsia*.

Challenges:

- ♦ To help patients to have more facilities for knowledge and find more access to treatment including surgery
- ♦ We don't have facilities for patients with economic problems.

Future Plans:

To establish a foundation to get money for better help of all the patients in my country.

Officer Election Date: February 11, 2019

EL SALVADOR: Salvadorean League Against Epilepsy

Report By: Ovidio Solano Cabrera (Vicepresident)

Summary of Activities:

The Salvadoran chapter of the International League Against Epilepsy (CASALICE) began a new stage since the election of its new authorities in May 2017; since then, a series of academic awareness and education activities in epilepsy have been carried out. These activities have been directed to medical personnel (general and specialists), medical students, and paramedics with the aim of contributing and updating the knowledge of the diagnosis and treatment of this disease, sometimes managing to attract audiences of more than 200 people. These have been carried out in different hospitals in the capital city and some in the interior of the country.

In May, the first meeting of the chapter with the national epilepsy commission of the health ministry of El Salvador was held for the first time in the history of our country. In this meeting a verbal collaboration agreement was

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established with this entity to be able to advise and accompany the government in the efforts that are carried out in order to improve the quality of life of our population with epilepsy. We hope that this agreement will be formalized soon. In addition, the creation of a group of patients and relatives of patients with epilepsy who meet monthly, in order to take epilepsy out of the shadows, educating and raising awareness among individuals about this disease.

With the same purpose, the social networking pages of patients with epilepsy and the Salvadoran chapter against epilepsy were recently created, which will help us in disseminating our activities.

As a chapter we know that the challenge is great and we have a lot to do, but we have only just begun and we have the desire to continue.

Challenges:

1. To Grow the Membership and our economic resources.
2. Finalize the procedures of legal representation in the public ministry of our country.
3. Establish ourselves as the highest academic authority in regard to epilepsy in our country.
4. To have a permanent presence and impact in the different medical and academic circles of the country.
5. Become an advisory entity of health and advocacy policies in epilepsy in El Salvador, which improve the quality of life of our patients.

Future Plans:

- Continue our educational and awareness-raising work through conferences.
- Work in subcommittees to diversify the work of the chapter.
- Encourage the use of social networks as a communication, education and awareness tool in epilepsy.
- Carry out the first week of epilepsy in September with the support of ILAE-Latin America and ALADE, as well as the epilepsy course in the first level of care with the support of Epilepsy in Primary Care Health Task Force of the ILAE.

Officer Election Date: November 2021

FINLAND: Finnish Epilepsy Society

Report By: Terhi Pirttilä, Secretary, Finnish Epilepsy Society

Publications: None

Summary of Activities:

EDUCATIONAL ACTIVITIES:

National teaching courses:

In 2017 Finnish Epilepsy Society was one of the organizers in Nordic Congress of Clinical Neurophysiology & Kuopio Epilepsy Symposium 2017 that was held in 15.-17.3.2017 in Kuopio, Finland. Congress was organized in collaboration with Kuopio University Hospital, Finnish Association of Pediatric Neurology, the Finnish Society of Clinical Neurophysiology, University of Eastern Finland and Finnish Epilepsy Association. The themes in the congress were Evidence-based Clinical Use of TMS, Sleep as Individual and Global Concern, Long-term EEG-monitoring Services, Status Epilepticus Update, Predicting Seizures and Risk of SUDEP, Myoclonus, Genetics and Biomarkers for Epilepsy, Advances in Treatment I & II ja Clinical Neurophysiology in Critical Care Patients/Neurointensive Care. Lecturers were international and domestic experts in the field of epilepsy. The congress had 385 participants including lecturers.

In 2017 Finnish Epilepsy Society did not organize its own annual teaching course since its major contribution to the Nordic Congress of Clinical Neurophysiology & Kuopio Epilepsy Symposium.

17.-18.5.2018 "Refractory epilepsy - New insights to diagnosis and treatment of epilepsy – Vaikea epilepsia - uusien näkökulmien epilepsian diagnostiikkaan ja hoitoon". Visiting lecturer Dr Nicola Specchio from Italy gave a lecture entitled "Management of epileptic syndromes through stages of life" and Dr Rajiv Mohanraj's lecture was entitled "Outcome of new AEDs in refractory epilepsy". Professor Reetta Kälviäinen talked about the national guidelines for epilepsy diagnosis and treatment. The second day consisted of workshops dealing with topics

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such as SUDEP, co-morbidities of refractory epilepsy and indications of video-EEG monitoring. Eija Gaily and Reetta Kälviäinen talked about valproate medication as treatment of epilepsy in girls and women. A mini-symposium of super-refractory status epilepticus closed the course. Lecturers were domestic experts in the field. The course had 88 participants including lecturers. Feedback obtained from the course was good/excellent.

Local education courses:

Finnish Epilepsy Society has organized since 2006 local courses around Finland in collaboration with Eisai AB, Fenno-Medical Oy, Orion Pharma, Sandoz and UCB Pharma Oy Finland. The topics of the courses in 2017 were the new ILAE classification of seizures, challenges in epilepsy diagnostics, and rare epilepsies. In 2018 topic were epileptic syndromes through stages of life, and good management of epilepsy.

In 2017-2018 courses were organized in Helsinki (26.4.2017, participants 45), Turku (21.9.2017,48), Pori (5.2.2018,18), Kotka-Lappeenranta (7.3.2018, 21), Oulu-Rovaniemi (video) -Kemi-Kokkola-Kajaani (webinar) (16.10.2018, 27-12-12), Helsinki (14.11.2018, 27).

MEETINGS:

Society organizes every spring annual meeting that is open for all members of the society. Annual report, financial statement of the previous year and action plan for the next year are presented and approved in the meeting. New board members are also selected annually for one year period. The annual meeting in 2017 was held on 17th March 2017. 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 (Kirsi Mikkonen). The same members were selected to continue in annual meeting 2018 that was held 18th May 2018.

Board meetings:

The board members of the society in 2017-2018 were Reetta Kälviäinen (president), Terhi Pirttilä (secretary), Henna Jonsson (treasurer), Salla Lamusuo, Riikka Mäkinen and Päivi Olsén. The board organized meetings 4 to 5 times annually.

INTERNATIONAL COLLABORATION:

Finnish Epilepsy Society is the Chapter of the International League Against Epilepsy (ILAE). Members of the society have several international positions: professor Jukka Peltola is a member of ILAE Classification and Terminology Commission and professor Reetta Kälviäinen is a chairwoman of Epilepsy Scientific Panel of European Academy of Neurology (EAN).

DOMESTIC COLLABORATION:

Members of Finnish Epilepsy Society participate in the national committee to create guidelines for the treatment of epilepsy in Finland (Käypä Hoito- committee). In 2016 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).

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 240 members (in 31.12.2018). In 2017-2018 the society did not collect membership fee.

Challenges:

To recruit new members to the board activities.

Future Plans:

In 2019 Finnish Epilepsy Society will organize a national educational course in March in collaboration with Finnish Association of Pediatric Neurology. The course is held at Tahko Ski Resort in Kuopio. The annual meeting of the society is organized in March 2019 at Tahko, Kuopio. Local educational courses will also be continued in the coming year. Society continues to collaborate with Finnish Epilepsy Association to promote the knowledge of epilepsy and equal access to high-quality care in Finland.

Officer Election Date: 22.3.2019

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FRANCE: French League Against Epilepsy

Members of the Board of Directors: Stéphane Auvin, Fabrice Bartholomei, Stephanie Baulac, Hélène Brissart, Serge Chassagnon, Philippe Derambure, Sophie Dupont, Edouard Hirsch, Virginie Lambrecq, Louis Maillard, Cécile Marchal, Benoit Martin, Renaud Michel, Vincent Navarro, Marie-Christine Picot, Marielle Prevos- Morgant, Sylvain Rheims, Philippe Ryvlin, Louise Tyvaert.

The LFCE Board of Directors met at the JFE in Marseilles, France in 2017, and then in May 2018 in Lyon, France.

1. The President's report

The President, Philippe Derambure, highlighted:

- the work with the public authorities (task force, revaluation of the EEG pricing, MEG pricing)
- the work of the different LFCE commissions (advanced practice nurse, communication, scientific council, training, therapeutic education, telemedicine, psychiatry in constitution) that still needs to be optimized
- the reconciliation with other Scientific Societies: SFN and the French Federation of Neurology
- the necessary questioning of the independence from the industry or of its transparency in case of partnership

2. Bureau

Since May 2018, between meetings of the Boards of Directors, the bureau consisting of:

- ♦ Treasurer: B Martin
- ♦ Scientific Committee : S Rheims
- ♦ International Affairs : Ph Ryvlin
- ♦ Communication: V Lambrecq
- ♦ IDE (nurse practitioner): M Prevos-Morgan
- ♦ Networks: F Bartolomei
- ♦ Secretary General: S Dupont Has held regularly conference calls.

3. Communication

Several points should be noted:

- a) an active redesign of the LFCE website is underway to enhance the visibility of the LFCE and its actions, to provide a forum for the actions on epilepsy. The tender was handed to Expression santé. Three website sections, currently being drafted, were decided:
 - General public section (LFCE officials: Laurent Vercueil, Virginie Lambrecq)
 - Professionals public section (LFCE officials: Louise Tyvaert, Sophie Dupont)
 - Members section (LFCE officials: Nathanaëlle Touchon, Benoît Martin)
- b) following the discontinuation of "Cahiers de l'Épilepsie" (Journal of the LFCE), articles related to oral communications selected from the JFE could be published in the "Revue Neurologique" (special issue or dossier according to the numbers of articles received). The applications have been made and accepted by the authors, we are awaiting the return of the articles (LFCE officials: Sylvain Rheims, heads of Revue Neurologique: Laurent Vercueil, Sophie Dupont)
- c) scientific council: the grants: this year, 3 grants will be awarded, 11 files re- submitted, the oral assessment was made on 07/06/2018 in Lyon, France by a jury composed of scientific council members after a first assessment of the files. The three winners will be announced at the JFE.
- d) Meetings:
 - The JFE in Marseilles took place from October 9 to 12, with great success and substantial financial surpluses. The subsequent JFE took place in Lyon from October 16 to 19, 2018. A call for poster or oral presentations has been launched; the free communication session is again jointly organized with the Jean Bancaud's day. Paris has been selected for the JFE 2019.
 - JNLF: on the agenda of the LFCE session in 2019, practical epileptology workshops with only clinical cases, a video session and a scientific session on the management of the first seizures will be organized
 - A French application for the organization of the European Congress of 2020 being considered, will require postponing the JFE that year

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4. Task Force:

Several meetings were held with Emmanuelle Alloneau-Roubertie, at the French Ministry of Health.

The HAS (French National Health Authority) mandated the LFCE to:

- 1) Write a guide for the care management pathway for epilepsy (in association with the FFN (French Federation of Neurology), the CNAM (French national health insurance fund) and the HAS).
- 2) Write a recommendation on the management of epilepsies in adults and children (the bibliographic referencing started)

5. Training

Several points:

- a) The DIU (inter-university diploma): the annual examination is validated for the new school year in 2019 with web-based course platform and hands-on sessions of clinical cases and exchanges of experiences to be organized locally. Thus, classes still need to be recorded in the meantime.
- b) We are still thinking about obtaining an ODPC (Continuing Professional Development Organization). Reconciliation took place with neuroDPC (an arm of the FFN) with Thomas de Broucker and Guy Chauplannaz. NeuroDPC has been approved in early April, and enables the societies to register through it. Several types of programs, FMC and assessment of practices already exist. This might help avoid (in part) the cumbersome DPC file.
- c) Telemedicine: Pr T Moulin: president of the Société Française de Télémédecine - (referent Scientific Society for telemedicine in France) proposes a partnership with the LFCE (in return for a membership financial contribution that was approved by the LFCE). As a reminder, the Société Française de Télémédecine (SFT) was founded in 2007 with 4 fields: scientific (medical, relation with Scientific Societies), ICT-engineering, professional health organizations (boards, associations, and institutions), law/economy/human and social sciences. The common projects would deal first with: 1) advice on the EEG practice in telemedicine, 2) epileptologic

teleconsultation in connection with the transmission of the EEG. A telemedicine working group was chosen to interact with the SFT: VN, SA, CM

6. International affairs:

As a reminder, E Trinká is the new European chair and Sam Wiebe is the new president of ILAE. The European Young Investigator Award was given to Sylvain Rheims, and E Perrucca received the life achievement award

7. Therapeutic education, nurse practitioner (IDE)

The TPE (Therapeutic Patient Education) Commission and the TPE seminar were successfully conducted this year in Lyon, France, with many registrants. The next session will take place in Paris.

The other healthcare professionals' session at the JFE works perfectly.

The decree is published on IS status. The objective is to integrate nurse practitioners (IDE) in the management of epilepsy patients, to improve the organization of health care, and to reduce the stigma of epilepsy. In order to obtain an IS status, a TPE training (40 hrs.) and an 88-hour training in clinical reasoning are required.

The status of IPA (advanced practice nurse practitioner) was also formalized: it requires an additional and nationally recognized training (master 2) and wage increase. The epilepsy is part of the chronic disease module proposed in the training.

8. Neuropsychology guidelines

As a reminder, the aim is to harmonize practices in neuropsychological assessments performed during the surgical treatment. A working group was established and met twice during the JFE. It should initially work as recommended by the HAS for the recommendations of clinical practices but this was impossible due to the low level of evidence of the selected articles. Thus, another methodology will be implemented more in line with expert opinion. An additional budget of €12,000 was allocated for pursuing this task (2018-2019).

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9. Financial report

The result of the JFE in Marseilles shows a larger surplus in the financial balance. The number of small partnerships rises during the JFE, but we bear in mind a reduction of the number of contributors, donations and an increase in meeting costs and website costs.

GEORGIA: Georgian Chapter of the ILAE (GE-ILAE)

Publications:

1. Zhizhiashvili L., Japaridze G., Lomidze G., Kasradze S. Effect of Levetiracetam on EEG activity and menstrual cycle regularity in women with epilepsy. Zhizhiashvili L., Japaridze G., Lomidze G., Neurophysiology (in press)
2. Gogatishvili, Khachapuridze N., Ediberidze T., Lomidze G., et al., Autism and Autistic spectrum disorders in children with fetal antiepileptic drugs exposure. *Therapia*. 2017;1(6):40-43 (Georgian).
3. Silagadze K., Kasradze S. Psychogenic non-epileptic seizures. *Therapia*. 2017;1(6):12-14 (Georgian).
4. Gogatishvili N., Khachapuridze N., Japaridze G., Kasradze S. Epileptic seizures and EEG future in children with fetal antiepileptic drugs exposure. *Clinical and Experimental Medicine* 2017;1:72-76 (Georgian).
5. Mosiashvili Zh., Kasradze S., Gagoshidze T. Working Memory Deficit in Patients with Temporal and Frontal Lobe Epilepsy (2017). *JSM Brain Science* 2(2):2015.
6. Alkhidze M., Lomidze G., Kasradze S., Tsiskaridze A. Characteristics and predictive biomarkers of drug resistant epilepsy - study in Georgia. *Neuroimmunol Neuroinflammation* 2017;4:191-8.
7. 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 Behav.* 2017 Jan;66:105-112. doi: 10.1016/j.yebeh.2016.10.014.
8. Gogatishvili N. Khachapuridze N., Ediberidze T., Lomidze G., Mamukadze Sh, Gagoshidze T., Kasradze S. Different aspects of cognitive functioning and Autism in Children with anticonvulsive exposure during pregnancy. *Experimental and Clinical Medicine* 2017;

1:40-43 (Georgian)

9. Silagadze K., Kasradze S. Psychogenic non-epileptic seizures. *Therapia (Georgian)* 2017; 1(6):12-14.
10. Gogatishvili N., Khachapuridze N., Japaridze G., Kasradze S. Epileptic seizures and EEG-future in children with anticonvulsive exposure during the fetal period. *Experimental and Clinical Medicine* 2017; 1:72-76 (Georgian)

Guidelines:

- Guideline – Diagnosis and Treatment of Epilepsy (Kasradze S., Kvernadze D., Lomidze G) (2017)
- Guideline – Diagnosis, Treatment and Management of Status Epilepticus (Kasradze S., Kvernadze D., Alkhidze M., Jishkariani T., Ediberidze T. and Gogatishvili N.) (2017)
- Protocol – Management of the first unprovoked seizure (Kasradze S., Kvernadze D., Lomidze G) (2017)
- Protocol-Epilepsy Management at Primary Health Care Settings (Kasradze S., Kvernadze D., Lomidze G., Silagadze K)(2017)
- Protocol - Neuro-imaging for Patients with epilepsy (Kasradze S., Okujava M., Lomidze G.)(2017)
- Protocol – Protocol for Imaging infants and children with new-onset epilepsy (Kasradze S., Okujava M., Lomidze G.)(2017)
- Protocol – Diagnosis and Management of Pharmacoresistant Epilepsy (Kasradze S., Kvernadze D., Alkhidze M., Lomidze G.)(2017)
- Protocol – Management of the Convulsive Status Epilepticus (Tatishvili N., Shatirisahvili T., Kipiani T., Dikhamindjia N., Tujishvili M., Chikvinidze G.)(2017)

Summary of Activities:

Important News:

- ROW foundation handed Video-EEG to Georgian Epileptologists for investigations of people with epilepsy and promotion of Epilepsy Surgery services in Georgia (2018). Please see the photo gallery in the Georgian Spotlight
- Epilepsy surgery was launched in October 2018 in Georgia, in a frame of the German-Georgian Project:

Chapter Reports *(continued)*

“EpilepCure Hallmarks of epileptic brain activity”. In collaboration of the German and Georgian professionals was performed epilepsy surgery by the non-invasive protocol (right-side MTS, one case) and by invasive protocol – EEG with foramen ovale electrodes (bi-lateral MTS, one case)

- ILAE-Georgian chapter and Georgian Epilepsy Prevention and Control Centre in collaboration with Georgian Ministry of Health elaborated National Program on AED-supply for people with epilepsy (Carbamazepine, Valproate, Lamotrigine and Levetiracetam - free for patients)(2018)
- Georgian Epilepsy Prevention and Control Centre elaborated “EpiSoft” - e-Health format for Diagnosis and follow-up Management of Epilepsy (was launched in 2018).
- ILAE-Georgian Chapter and Georgian Epilepsy Prevention and Control Centre Translated and adapted EEG-Score format in Georgian.
- ILAE-Georgian Chapter established “GLAE Lifetime Achievement Award in Epilepsy” that will be given to one person in a year, which will have a special and significant personal contribution and activities that promote the development of epilepsy education in Georgia.

Conferences and meetings

- ILAE/ILAE-Europe and ILAE-Georgian chapter’s Pre-conference symposia “Infantile epilepsy in light of new ILAE classification-new terminology, etiology and treatment perspectives” (<https://eacd2018.net/pre-conference-symposia/>) in a frame of the 30th International Conference of European Academy of Childhood Disability (EACD2018, Hotels & Preference Hualing Tbilisi, Tbilisi, Georgia) (<https://eacd2018.net/>)
- 3rd Caucasian Course in Child Neurology – Epilepsy (EPNS2108, Tbilisi, Georgia). Organizers Tbilisi State Medical University, Association of Child Neurology and Behavioral Disorders and European Pediatric Neurological Society (2018).
- Achievement of new board members of ILAE-Georgian chapter (2018)
- Local Meetings of GLAE members (once per year)
- 1st Conference & Workshop of the German-Georgian Project: “EpilepCure Hallmarks of epileptic brain activity”,

Georgian National Academy of Science, Tbilisi, Georgia (2017)

- Plenary session on pediatric/adult epilepsy care in a frame of Local Conference (Annual Meeting) of Georgian Academy of Neurology, Tbilisi, Georgia (2017) Education
- Six graduates of 1st Educational Course on Clinical Electroencephalography accredited by Georgian MoH as a EEG-sub-speciality (duration 8 months)(2018);
- Training of EMU-group - one month intensive training of epileptologist, clinical electrophysiologist and neurosurgeon in February, and one month intensive training of epileptologist, clinical electrophysiologist, neuropsychologist, clinical manager in November on the base of Epilepsy Center Berlin Brandenburg, Charité Universitätsmedizin Berlin, Germany in a frame of the German-Georgian Project: “EpilepCure Hallmarks of epileptic brain activity” (2018)
- Translation of the new classification of epileptic seizures (2018)
- Educational conference on New Classifications of Epilepsies for its implementation (2018)
- Meetings regarding “News in Epileptology” on the base of Epilepsy Centre (every month)
- German-Georgian TV-conferences regarding case-reports for Pre-surgical Evaluation of good candidates for epilepsy surgery among people with drug-resistant epilepsy in a frame of German-Georgian Project: “EpilepCure Hallmarks of epileptic brain activity” on the base of the Epilepsy Prevention and control Centre, Tbilisi, Georgia - one per three months (2018);

ILAE/VIREPA/other - teaching courses –young physicians were trained EU countries and in USA on

- clinical epileptology
- EEG investigations (basic, clinical –pediatric/adults, sleep-EEG, EEG-score)
- New antiepileptic drugs (EILAT)
- Ketogenic diet
- High frequency oscillations (DAAD-program in Cellular and Network Physiology Lab Charité Universitätsmedizin Berlin)

Chapter Reports *(continued)*

- MRI/fMRI-Epilepsy Protocol
- Epilepsy surgery (pre-surgical evaluation and surgery)

Research

International

- EURAP-NCEP- “EURAP extension protocol No. 2, Neuro-Cognitive Extension Protocol (NCEP) for children exposed to antiepileptic drugs in utero” (2018 -ongoing)
- German-Georgian Project: “EpilepCure Hallmarks of epileptic brain activity” (Donor – Ministry of Education and Sciences of Germany)
- EP0034 – Multicentre, open-Label, Long-term extension study to investigate the efficacy and safety of Lacosamide as adjunctive therapy in pediatric subjects with epilepsy with partial-onset seizures (Phase 3)(UCB Biosciences Inc).
- SP0969-Multicenter, double blind, randomized, placebo controlled, parallel group study to evaluate the efficacy and safety of lacosamide (LCM) as adjunctive therapy in subjects with epilepsy ≥ 4 years to < 17 years of age with partial-onset seizures (Phase 3)(UCB Biosciences Inc).
- SP-0967 -Multicenter, double-blind, randomized, placebo-controlled, parallel-group study to evaluate the efficacy and safety of Lacosamide as adjunctive therapy in subjects with epilepsy ≥ 1 month to < 4 years of age with partial-onset seizures (Phase 3)(UCB Biosciences Inc).
- Five pragmatic random studies comparing Levetiracetam effectiveness with Lamotrigine, Carbamazepine and Sodium Valproate in newly diagnosed untreated epilepsies (EpiNet Study)
- EURAP- European Registry on Antiepileptic Drugs and Pregnancy (2001-ongoing).

Local

- Epidemiology and risk-factors of pharmaco-resistance epilepsy In Batumi Region
- Validation of a Georgian version of the Neurological Disorders Depression Inventory for Epilepsy (NDDI-E)
- Peculiarities of Depression and other psychiatric disorders in people with Epilepsy and (Founded by the Caucasus International University, Tbilisi, Georgia)
- Clinical Audit of Epilepsy Care in Gurjaani Region of Georgia (founded by the EU – Kakheti Regional

Development Foundation).

- Thesis “Stigma and Self-stigma in Adolescents with Epilepsy” (2017)
- Thesis “Cognitive functions in children exposed to anticonvulsants in utero” (founded by the Shota Rustaveli National Scientific Foundation)(2017)
- Thesis “Working Memory Deficit in Patients with Temporal and Frontal Lobe Epilepsies” (2017)

Services

- Epilepsy surgery was started, EMU-Group is working in collaboration with International experts
- Long-term EEG -Telemetry and pre-surgical evaluation of people with drugresistant epilepsies was started in Georgia under the supervision of International Experts.
- Multidisciplinary (neurologist-epileptologist, neuropsychologist, psychiatrist, standard EEG, high resolution MRI) diagnoses center by the National Guidelines and Protocols (pediatric/adults) became a mandatory format;
- Up to 51% of people with epilepsy living in Georgia are investigated multidisciplinary by the ILAE recommendations (Engel, 2001) and registered in Epilepsy Registry at the Epilepsy Prevention and Control Centre of the Institute of Neurology and Neuropsychology (since 2005)
- Video-EEG monitoring was actively included in differential diagnosis of epilepsy and non-epileptic events.
- Basic genetic investigations was implemented in Georgia
- Established new Regional Group for multidisciplinary diagnoses of Epilepsy in Gori (Shida Kartlii region of Georgia)(2018).

Social events

- Conference for students and staff in David Tvildiani Medical University devoted to “International Epilepsy Day 2018” (2018)
- Organizing of “European epilepsy day” and “World Epilepsy Day” (in 2017)
- Public Lectures on Epilepsy in Regional PHC settings in Gurjaani (east Georgia, 6 lectures), in Kutaisi (west Georgia, 2 lectures), in Terjola (west Georgia, 1 lectures) (2018).

Chapter Reports *(continued)*

- TV-broadcasts on epilepsy (11 in 2018)

Awards

GLAE Lifetime Achievement Award in Epilepsy were given to

- Prof. Meir Bialer, Israel (2017)
- Prof. Federico Vigeveno, Italy (2018)

Challenges:

Lack of global vision of the epilepsy problem in health care system; lack of financial availability from Government for repeated investigations of patients (EEG, EEG-monitoring, drug monitoring, pre-surgical evaluation, MRI investigations, etc.), lack of availability on new/newest anticonvulsive drugs, other treatment methods (ketogenic diet).

Future Plans:

Evaluation of the Global State Program on Epilepsy from Primary Health Care Settings to tertiary Epilepsy Center, Promotion of the implementation the new anticonvulsive drugs, new diagnostic/treatment/care methodologies in Georgia

Evaluation and implementation of the training modules on Epilepsy for medical doctors regarding their competences

Activation of the association of the Georgian young epileptologists

Activation of the research on basic and clinical epilepsy

Officer Election Date: Next Election data 2022

GERMANY: German Society for Epileptology

Report By: Ingmar Blumcke

Publications:

Zeitschrift für Epileptologie (SpringerMedizin Berlin)

Summary of Activities:

The 54th annual meeting was held in Fürth, Germany from June 13-16, 2018 accommodating 900 registered

participants, 41 scientific platform sessions and 20 educational training courses. Dr. Herman Stefan was awarded the prestigious Otfried-Foerster medal. The meeting was accompanied by the epilepsy patient day on June 16, 2018 at the same venue.

In 2018, the German chapter granted 79 certificate for successful education. The chapter also granted several bursaries to allow young epileptologists to attend scientific meetings across Germany and 2 Otfried-Foerster fellowships were given to support training in epileptology.

In 2018, the Dieter Janz award from the Peter and Jyette Wolf foundation for the best scientific publication of a young German epileptologist was awarded to Dr. Barbara Schmeiser (Schmeiser et al. 2018, J Neurol 265:500-509).

The 8th International Summer School for Neuropathology and Epilepsy Surgery was held in Erlangen, Germany, July 26-29 accommodating 50 participants and 14 tutors from 27 countries. ILAE and ILAE-Europe granted 12 travel bursaries for attendees from resource poor countries.

Challenges:

The German ILAE and IBE chapters will join forces and work closely together to increase public awareness against stigma, discrimination and treatment gaps. The Epilepsy Day was organized by the German IBE chapter on October 5 in cooperation with the Brüderkrankenhaus in Trier, Germany (patronized by Dr. Katharina Barley, federal minister of justice and consumer protection).

Future Plans:

The 55th annual meeting will be jointly organized by the German, Austrian and Swiss ILAE chapters in Basel, May 8-11, 2019.

Officer Election Date:

Prof. Andreas Schulze-Bonhage (Freiburg, Germany) was elected as incoming president for the term 2019-2020.

GHANA: Ghana Epilepsy Society

Report By: Dr Albert Akpalu

Chapter Reports *(continued)*

Publications:

Ghana Fights Against Epilepsy Initiative (GFAEI) https://www.afro.who.int/sites/default/files/2018-11/WHO-Epilepsy-Ghana_web.pdf

Summary of Activities:

In Ghana, it is estimated that 1% of the population live with epilepsy, representing 270 000 people, with a treatment gap of 85%. It is in that context that the Ghana Ministry of Health, in collaboration with WHO, launched the Fight against epilepsy initiative in 2012. The goals of the five-year project were to improve the identification and management of people with convulsive forms of epilepsy within the existing primary health care system and to develop a model of epilepsy care at the community level that could be scaled up nationwide. The project was implemented gradually across five regions comprised of ten districts and 55 hospitals and clinics, in the following steps: (i) developing a strategy for delivering epilepsy care, (ii) training health care workers and volunteers, (iii) raising awareness and educating communities, (iv) engaging traditional and faith healers, and (v) strengthening monitoring and evaluation of epilepsy. Thus, in one Ghanaian site (Ashiedu Keteke, an urban region of Accra), the contact coverage (based upon a country prevalence of 1%) rose from 9.4% in 2012, to 25.7% in 2016, after instigation of the programme (WHO 2018). However, the coverage is still too low, and further measures are needed to increase it. Therefore, better understanding of the perceptions of epilepsy and the barriers to implementation of the kit need to be examined, particularly in urban communities. Disentangling differences between those experiences in urban and rural societies might then open the opportunity to enable local health leaders to design appropriate healthcare models for each.

Challenges:

- Access and availability of funds to implement activities
- Sustainability and nationwide roll out of GFAEI programs

Future Plans:

To engage in an Epidemiological study (Epilepsy Innovation Study in Africa)

A clear opening to improve the care of PWE resides in the fact that mobile technology is advancing rapidly throughout

LMICs. Training PHWs in basic epilepsy diagnoses and then enabling them to capture phenotypic data on mobile devices that can, through algorithms, determine the most appropriate patient pathway may reduce the diagnostic gap. This would also offer a methodology for non-physicians to operate in non-medical environments. Moreover, the use of health-related short messaging services (SMS) has found traction in SSA and offers a medium to improve adherence to AEM. The underpinning of these aspects in App-based technologies future-proofs the proposed project supporting an enduring benefit to the local populations.

Officer Election Date: September 2019

GUATEMALA: Guatemala League Against Epilepsy

Report By: Mario Alfonso Juarez Barrera

Publications:

No se realizaron publicaciones de artículos científicos

Summary of Activities:

- Una reunión al mes en donde se exponen actualizaciones en cuanto a epilepsia con todos los miembros del capítulo, dirigidos y organizados por la junta directiva.
- Programa de socialización en contra de la epilepsia en apoyo al Ministerio de Salud Pública de Guatemala. Miembros del capítulo impartieron una conferencia/taller sobre la epidemiología, factores de riesgo por edad, tipos de crisis epilépticas (con videos), tratamiento con fármacos antiepilépticos, pronóstico y prevención. Las conferencias se realizaron en centros de primer y segundo nivel de atención, en donde no hay neurólogos. En los departamentos.
- Curso básico mhGAP sobre Epilepsia/Convulsiones impartido por miembros del capítulo, en diferentes centros de primer y segundo nivel de atención. En los departamentos.
- Congreso anual de enfermedades neurológicas en donde se invitan a expositores internacionales, tratando varios temas concernientes a epilepsia. Siempre en el mes de septiembre con duración de una semana.
 - o Septiembre 11 al 15 del 2018
- Taller mensual a pacientes con epilepsia sobre la importancia de la toma de sus medicamentos, los efectos secundarios, apoyo emocional y actividades grupales.

Chapter Reports *(continued)*

Challenges:

- Contar con fenitoina, ácido valproico, carbamazepina y fenobarbital en los centros y puestos de salud (primer y segundo nivel de atención) así como en los Hospitales de tercer nivel, que sean adquiridos por el Ministerio de Salud Pública y sean entregados de forma gratuita a los pacientes.
- Lograr que los médicos generales de atención primaria y secundaria puedan identificar un síndrome epiléptico e inicien su manejo, teniendo claro cuando es necesario referir al paciente a un tercer nivel de atención. Esto mediante las conferencias/talleres realizadas en múltiples ocasiones.
- Incentivar a la investigación científica sobre epilepsia y la publicación de los artículos.

Future Plans:

- Continuar dando acompañamiento al Ministerio de Salud Pública en temas referentes a epilepsia.
- Seguir con las capacitaciones y reforzamiento de la epilepsia en los centros de atención primaria y secundaria.
- Proponer y exponer al Ministerio de Salud Pública la importancia de contar con los antiepilépticos básicos en los tres niveles de atención para que sean gratuitos.
- Crear un banco de medicamentos antiepilépticos en el Hospital General San Juan de Dios.

Officer Election Date: January 15, 2019

HONG KONG: Hong Kong Chapter of the ILAE

Report By: Howan Leung

Publications:

Updated review: drug resistant epilepsy and presurgical evaluation of epilepsy surgery - Consensus statement by Hong Kong Epilepsy Society HKMJ 2018; Nov 27 doi: 10.12809/hkmj187285. [Epub ahead of print]

Summary of Activities:

2018 has been a year of watchful duties and loyal service to our patients and professionals. We provided support to our fellow doctors, nurses, clinical psychologists, technicians and academics. We have given help to our community to increase the awareness of epilepsy in general.

Annual Scientific Meeting and Quarterly Scientific Meetings

Three quarterly scientific meetings (QSM) and one annual scientific meeting (ASM) were held under the auspice of the Hong Kong Epilepsy Society.

- The first QSM was delivered by Dr XL Zhu on the subject of deep brain stimulation for epilepsy. It was an interesting evening as Dr Zhu shared his clinical experience in this modality of surgical intervention.
- The second QSM was delivered by Dr Piter Lo (Radiologist), Dr Iris Chan (Clinical Psychologist) and Dr TL Poon (Neurosurgeon) on language mapping in presurgical evaluation of epilepsy, from perspectives of different specialties. Hitherto, the treatment of epilepsy with surgery could not be accomplished without a reliable means of testing the eloquent area. The latest technologies and clinical psychological support were exemplified by them in their remarkable presentation.
- The third QSM was delivered by our honorable guest Dr Ching-Choi Lam, a member of the Executive Council, and also the Chairman of Elderly Commission in Hong Kong. An open forum was held during this occasion and many pieces of valuable opinion were gathered in the process. What's more, Dr Lam reflected on the various healthcare strategies that the government was contemplating, including that of a model of a case manager. The highlight of Dr Lam's talk was that any model of care with an embracing solution was usually the one that would be highly considered or appreciated by the government.

Towards November, we came to the ASM, which was the essence of our annual academic activity. Dr Gavin Winston from Queen's Square, London, lectured us on the radiological techniques for presurgical evaluation, whereas Prof Wenjing Zhou from Beijing shared with us knowledge about thermocoagulation technique using SEEG.

Academic Study and sponsorship of conferences

We have sponsored Dr KW Fong from Queen Elizabeth Hospital to engage in an attachment with Prof Andrew Cole of Harvard Medical School. The underlying theme was to learn about presurgical evaluation and handling complex and difficult epilepsy cases.

We sponsored several members to attend short courses/meetings:

Chapter Reports *(continued)*

5. Summer School on Imaging in Epilepsy (SuSIE) (Marburg, Aug 2018)
6. 18th Asian Oceanian Epilepsy Congress (Indonesia, Jun 2018)
7. Seventh Cleveland Clinic Brain Mapping Workshop (Cleveland, September 2018)
8. "EEG in the first two years of life" (Cambridge, Apr 2018), 5. 13th European Congress of Epileptology (Vienna, 2018)

A number of ad-hoc meetings were co-organized by HKES. A webinar event was co-hosted with GSK on the treatment of drugs with experts from Saudi Arabia (Sep 2018). Two events were organized with UCB on drug treatment: one was delivered by Prof Michel Baulac (April 2018) and the other was the highlight of post-ECE (European Congress of Epileptology) (Oct 2018) given by members who had attended the meeting. A Novartis co-hosted inter-hospital epilepsy surgery meeting was held in May 2018, with the aim of discussing interesting and difficult epilepsy surgical cases among professionals across the territory. An Eisai co-organized meeting took place in May 2018 with Prof Pierre Genton (France) and Prof Ziyi Chen (Guangzhou) as guest speakers.

Engagement with community

On February 11, 2018, we hosted a local event in line with the International Epilepsy Day (IED). This event was organized jointly among Hong Kong Brain Foundation, Hong Kong Neurological Society and Hong Kong Epilepsy Association. A special event, which was held in The I-bakery of the Government Building at Timar, marked the inception of our event. Our hosts of the day included TV hosts Marcus Kwok and Fong Kin-ye. The Hong Kong Epilepsy Association, a major patient group campaigning for epilepsy, has been working hand-in-hand with us. The event promoted the awareness of epilepsy in Hong Kong and it was the first of its kind in HK.

Publications

Following the publication of the first two consensus statements, the third one was published in 2018, under a subcommittee led by Dr TL Poon. The topic was refractory epilepsy/ presurgical evaluation of epilepsy. It was published by The Hong Kong Medical Journal. ([link](#))

Challenges:

1. To promote research and teaching of epilepsy among young professionals
2. To sustain community engagement of epilepsy awareness

Future Plans:

1. More academic support for professionals
2. International Epilepsy Day

Officer Election Date: January 22, 2019

HUNGARY: Hungarian Chapter of the ILAE

Summary of Activities:

- One national congress (April 2018) and one epilepsy educational program (October 2018).
- Educational scholarship for two young clinical epileptologists (2017-2020).

Challenges:

Availability and support of some AEDs.

Future Plans:

Further educational scholarships announced.

Officer Election Date: October 2019

Report By: Andras Fogarasi (President)

IRAN: Iranian Chapter of the ILAE

Summary of Activities:

Since our chapter was officially recognized in September 2017, we have established headquarters in the Iranian neurological association and our website is set up (<http://iranilae.org/>). Apart from the core committee including the five constituent members, we have enrolled 86 united members that are mainly adult and pediatric neurologists and epileptologists.

Through several meetings the vision and missions for the upcoming year were determined. Our priorities were to firstly, announce the chapter nationwide and recruit members; secondly, develop national epilepsy guidelines

Chapter Reports *(continued)*

with collaboration of the ministry of health that covers the epilepsy management and diagnostic investigation protocols; and thirdly, to hold international and local epilepsy congresses and workshops.

In order to achieve our goals, we reached out to the ministry of health officials and convinced them that the current official epilepsy guidelines were mostly nonexistent or inadequate and therefore, needed to be updated or adapted according to national circumstances. Fortunately, the ministry appreciated our cause and three taskforces were made including epilepsy guideline adaptation, standard of care protocol, and new epilepsy drug registry and implementation. Three workshops were held to train the taskforce members. Each task force consists of 20 academic united members who are currently involved in the process.

The 14th international Epilepsy Congress of Iran was held in February 2018 in Isfahan for three days exclusively on epilepsy.

The 24th international Congress of Neurology & Clinical Electrophysiology of Iran was held in Tehran in May 2018, with a six-hour epilepsy teaching course and workshop.

Brain and mood day conference was held in Tehran in December 2018 with collaboration of our chapter and the neurology, psychiatry and epilepsy associations. Several local epilepsy workshops were also held in Tehran, Tabriz, Mashhad, Karaj and Isfahan.

Four tertiary epilepsy referral centers are operating in the country and three epilepsy fellowship programs trained four epileptologists in 2018.

Challenges:

Unfortunately, due to current economic sanctions on Iran, there is shortage of medicine and medical instruments and accessories that has affected the epilepsy care in the country. Moreover, we should reschedule some of our deadlines due to the economic considerations. Despite these shortcomings, we are truly optimistic that we can improve the epilepsy care in our country and step towards our goals with international cooperation.

Future Plans:

1. National epilepsy registry
2. Iranian epilepsy journal

3. Regional epilepsy schools
4. General assembly meeting and election

Officer Election Date: We have not yet had an election.

Report by: Mahmoud Motamedi

IRAQ: Iraqi Society Against Epilepsy (IqLAE)

Report By: Dr Ghaieb Bashar Aljandeel/Sec General of IqLAE/Member of ILAE-EMR

Publications:

A number of publications were published by different members of the chapter including neurologists, neurophysiologists, pediatricians and psychiatrist through 2017 and 2018; most of them are published in Iraqi journals

Summary of Activities:

The chapter held monthly meetings throughout the year as a usual teaching attitude usually presented by members of the chapter about epilepsy issues or by guest lecturers for subjects in common with other specialties like gynecologists, psychiatrists and others.

A number of symposia or conferences were held by the chapter within 2017 and 2018 among them are the following:

- August 10, 2018: One day conference about Video-EEG cases and Video-EEG challenges
- February 23, 2018: One day conference about new classifications of both epileptic seizures and of epilepsy
- December 5, 2017: a symposium held at Central Child Hospital; the main subjects were about refractory epilepsy and epileptic encephalopathies
- October 15, 2017: A symposium held at Al-Elwya Children's Hospital; the subject was Electro-clinical Syndromes in Neonate and infantile periods
- April 14, 2017: One day conference; the main subjects were MRI protocols in Epilepsy imaging, Syncope Vs Epileptic seizures, and newer alterations in Epileptic seizure classification
- March 3-4, 2017: Two day International conference: The 1st Iraqi-Indian Conference in Epilepsy and Epilepsy

Chapter Reports *(continued)*

Surgery held at Babylon Hotel. Different subjects were involved; among them was the epilepsy surgery and Iraqi-Indian collaboration in this issue

- March 26, 2017: Participation in the conference of Alkindi Medical College
- October 26-27, 2018: Participation in the 8th International Congress of Jordanian Society of Neurology and 6th Epilepsy Congress of Jordanian Chapter
- Participation in the 9th international conference of Lebanese society of neurology 2018
- October 2017: Participation in the 7th international conference of Jordanian society of Neurology and 5th Epilepsy Congress of Jordanian chapter
- October 2018: Participation in the 6th ELAE Epilepsy Congress in Dubai
- 5th ELAE congress in 2017
- August 2018: Participation in the 13th European Congress on Epileptology in Vienna

Challenges:

A lot of challenges are facing our duty in Iraq. Among them are the security situation, the costs of the newer AEDs, the poor compliance of patients mainly due to poor economic state of most of epileptic patients.

Future Plans:

The most important future activity for which we are now preparing is the celebration of the Purple Day on 26 March, the international day for supporting epilepsy and also the arrangements for a number of conferences

Officer Election Date: It was supposed to be last year but postponed to March 2020 because of the security situation.

IRELAND: The Irish Epilepsy League

Report By: Daniel Costello

Summary of Activities:

- ILAE/IEL expert day September 2018 with guest speakers Prof. Andrea Rossetti and Prof. Orrin Devinsky
- Promotion of membership of IEL- currently 87 active members

- Epilepsy Nurses study day May 2018
- Neurology SpR training day June 22nd 2018
- Quarterly council meetings
- Participating in UK chapter meeting [Dr Daniel Costello]
- Annual Kirker prize for Epilepsy-orientated research in Ireland, presented at Irish Neurological Association meeting May 2018
- Regular promotion of ILAE-endorsed educational activities among IEL members

Challenges:

- Establishment of charity status for Irish chapter
- Establishment of secure funding stream for annual meeting

Future Plans:

- Annual Expert day November 15, 2019
- Neurology SpR training day June 2019
- Participation in Epilepsy Nurses training day May 2019
- Participation in IBE chapter ('Epilepsy Ireland') conference Sept 2019
- 2019 Kirker lecture as plenary lecture during IEL annual meeting
- 2019 Kirker prize for Epilepsy-orientated research to be presented at 2019 annual meeting of Irish Neurological Association
- Establishment of two travel bursaries to promote Irish epilepsy-orientated research

Officer Election Date: Next election of officers planned for October 2020

ITALY: Italian League Against Epilepsy

Report By: Laura Tassi, Vice-president

Publications:

Created and distributed a New Epilepsy Guide and Epilepsy and Woman Guide.

Chapter Reports *(continued)*

Summary of Activities:

1) The new chapter was elected in 2017 June, during the national LICE congress in Rome.

At present Members are: 867

- ✦ Members under 40 yrs = 375
- ✦ Members under 35 yrs = 271

After the last election, the Chapter has established 12 Commissions, with the exception of the institutional ones, including:

- ✦ Epilepsy surgery
- ✦ Epilepsy and gender
- ✦ Epilepsy and Internet
- ✦ Pharmacology
- ✦ Genetics
- ✦ Guidelines
- ✦ Neuroimaging
- ✦ New Syndromes
- ✦ Status Epilepticus
- ✦ Transition
- ✦ Video Gallery
- ✦ Educational

Nine task Forces have been created:

- ✦ Cannabis
- ✦ Neonatal convulsion
- ✦ Diet-therapy
- ✦ Epilepsy and headache
- ✦ Epilepsy and Cerebral tumors
- ✦ Dys-immune epilepsies
- ✦ Narrative medicine
- ✦ Neuropsychology (adult and children)
- ✦ SUDEP

Each committee or study group organizes meetings, guidelines, workshops, and dissemination.

2) The website was completely renewed! A very active web

site: www.lice.it is now available to all, and to the Members are dedicated many sections of education and Video-Gallery.

A Clinical Video-Gallery with many difficult to solve or scholastic cases are available, including the clinical anamnestic history, the EEGs and the Neuroimages.

A very new Surgery Video Gallery was uploaded few months ago, permitting also to neophytes to approaches with neurosurgical techniques, including electrodes implantation, surgical resections and disconnections. A link with ILAE Website would be really useful.

On the home page a banner linking to ILAE site “to be constantly up to date”

3) Every year the Chapter organizes a National Congress (in June) and a case discussion Meeting (in Rome, January).

RIUNIONE POLICENTRICA – annual meeting - Roma, 2018 January 25th – 26th

420 participants

ANNUAL NATIONAL CONGRESS 2018 Roma, June 6th – 8th

523 attendees of which 75 youth projects (free registration allowed)

4) The Chapter has set up 4 prizes for young people, of 2,500 euros, with which international courses will be paid that are held in Italy (San Servolo International Summer Course, Tagliacozzo International Course, Venice Stereo-EEG International Course).

5) With a three-year rotation organization, the LICE courses are Scheduled, free for members: Genetic, EEG and Neuroimaging.

- ✦ EEG COURSE Bologna, 2017 October 14th – 19th, 24 participants

- ✦ NEUROIMAGING COURSE (organized by the LICE Neuroimaging Commission) Bologna, 2018 October 7th – 10th, 70 participants

- ✦ GENETIC COURSE (organized by the LICE Genetic Commission) Milano, 2019 February 14th – 16th, 50 participants

Chapter Reports *(continued)*

- 6) The LICE Foundation collected enough last year enough to fund four projects of € 15,000 each, for a period of one year, dedicated to Chapter members.
- 7) Italy is subdivided in Regions. The Chapter created three independent Regions and seven Macroregions, in which smaller regions are aggregated to larger regions. Each area has its own coordinator who is in charge of following the dissemination, of creating scientific events, of finding new members, of organizing the International Epilepsy Day.
- 8) A very new YES Section was created. Only members under 40 can participate. They have reserved elections, different rules, a dedicated space on the website, set aside funding, and reserved a workshop during the national congress.
- 9) The Italian translation of the new ILAE Classification of 2017 is almost complete

Challenges:

The Italian Chapter is doing dissemination, creating scientific events, finding new members, and organizing new events for the International Epilepsy Day.

Future Plans:

The Italian Chapter submitted the expression of interest in hosting the ECE in 2022 in Italy.

Officer Election Date: 2020 June

IVORY COAST: Ivorian Association Against Epilepsy

Report By: Mariam Doumbia-Ouattara

Publications:

None

Summary of Activities:

The Ivorian League Against Epilepsy had few activities during these two years, consisting in education of specific groups of caregivers and sensitization of general population.

Summary of Activities in Relation to Global Campaign in 2017 and 2018:

- April 2017: Radio broadcast on local radios. Program:

Health for all. Theme: understanding epilepsy

- April 2018: Awareness program on a national television channel

Educational Activities

- February 2018: International Epilepsy Day. Theme: treatment of epilepsies
- October 2018: Pediatricians training day about diagnosis and management of epilepsies (2nd edition) in Abidjan

Challenges:

- Train physicians in epilepsy management
- Overcome stigma around epilepsy

Future Plans:

1. Revitalize the local association of professionals and the parents of epileptics
2. Continue the training of paediatricians, general practitioners and nurses in Abidjan and in provincial towns.

Officer Election Date: February 2017

JAPAN: Japan Epilepsy Society

Report By: Kosuke Kanemoto, M.D., Ph.D.

Publications:

- *Epilepsia* (3 publications a year)
- *Epilepsy & Seizure* (annual publication)

Summary of Activities:

Chapter meetings: The 51st Congress of the Japan Epilepsy Society (JES) in Kyoto, the 52nd Congress of JES in Yokohama

Advocacy: The part related to epilepsy in Questions & Answers about Epilepsy in the Workplace and the Americans with Disabilities Act (ADA) by U.S. Equal Employment Opportunity Commission was translated into Japanese, posted on the homepage of JES, and will be in *Epilepsia* 36(3). A seminar by a lawyer expert on problems related to the disabilities will be held in Tokyo on January 26, 2019.

Chapter Reports *(continued)*

Public outreach: International Epilepsy Day event was held in Tokyo on February 12, 2018.

Government liaisons: Ministry of Health, Labor and Welfare is unlikely to agree to the revision of Japanese drug information on anti-epileptic drugs regarding driving restriction. The Japan Epilepsy Society will organize research data derived using driving simulators in several institutions, in order to prove their use does not adversely affect patients' driving ability.

Challenges:

A project on the development of regional cooperation system of medical services on epilepsy (Regional Cooperation Project) was started in 2015 fiscal year by the Ministry of Health, Labor and Welfare, and will be expanded from 2019 fiscal year. There are political misunderstandings between JES and Japan Epilepsy Center Association (JEPICA). The JES President will make a proposal to JEPICA that the two organizations be constructively integrated within the next one to two years with transparency. An executive committee on the education of paramedical staff will be formed within JES and run by JEPICA. Discussion on the standardization of epilepsy centers and regional medical cooperation system will be done carried out in JES.

Future Plans:

JES plans to set criteria for epilepsy centers:

1. Number of long-term video EEG monitoring may be set to 30/year at minimum.
2. One of the medical experience criteria is to be 'provides expert medical service on the diagnosis and treatment of psychiatric problems accompanying epilepsy.'
3. 'Has an epilepsy clinic coordinator' may be added to the medical experience criteria in line with Regional Cooperation Project.
4. 'Holds a study meeting with epilepsy primary care physicians and/or a lecture open to the public at least 1/year' may be added to the medical experience criteria.
5. Hospitals that meet the criteria for a core hospital in Regional Cooperation Project may be considered as a quasi-epilepsy center. If more than one hospital functions as a tertiary center as a group, the group may be considered as a quasi-epilepsy center.

Officer Election Date: November 2, 2017

KOSOVO: Association Against Epilepsy in Kosovo

Report By: Valbona Govori, President

Summary of Activities:

- We organized activities for European Epilepsy Day (13 February 2017, 11, February 2018)
- The main activity during 2017 was organization of Seminar with International participation in collaboration with Kosovo Association of Neurology: Comprehensive approach to epilepsy, which took place in Prishtina 13 September 2017. It has been an honor to have Professor Meir Bialer among us, and his participation was highly valued by participants.
- The main activity during the term 2018 was organization of 3rd Epilepsy Symposium which took place in Prishtina 4th April 2018. It was held with 100 participants which they have opportunity to hear lectures given by the leading experts from Albania, Croatia, Macedonia.
- We also came up with a video sensitivities, with message living with epilepsy which was launched in three local media.
- Professional meeting, 10th September 2018 in the Department of Neurology –University Clinical Center of Kosovo, with residents, presenting case report regarding to epilepsy.
- We had professional meeting with GP Doctors, Primary Healthcare Workers, 11th February 2018 with topic Epilepsy: diagnosis and management in primary care.

Challenges:

The Association provides talks with healthcare professionals on epilepsy, also with patients and their families members.

Future Plans:

- Our plans are to promote epilepsy awareness and strength of our collaboration with Ministry of Health. Guideline of diagnosis and treatment of epilepsy where we still are waiting for answer from Ministry of Health.
- Creating data base of newly diagnosed patients with epilepsy.

Officer Election Date: 20th November

Chapter Reports *(continued)*

LATVIA: Latvian League Against Epilepsy

Report By: Jurgis Strautmanis

Publications:

One peer-reviewed article. Several local articles and presentations.

Summary of Activities:

- ✦ Two half-day conferences.
- ✦ Translation of the new classifications on seizures and epilepsies into Latvian.
- ✦ Translation of EEG terms into Latvian.
- ✦ First VNS implantation patients.

Challenges:

- ✦ Limited sponsorship possibilities.
- ✦ Limited access to video EEG monitoring, epilepsy surgery for adults.
- ✦ No reimbursement of VNS for adults and children.
- ✦ No reimbursement of novel AEDs for adults and limited for children.

Future Plans:

- ✦ One or two half-day meetings.
- ✦ Negotiations with government on VNS reimbursement and access to epilepsy surgery for adults.

Officer Election Date: 2021

LIBYA: Libyan Scientific Society For Epilepsy

Report By: Majdi Kara, Secretary General

Summary of Activities:

During 2017 the main activity was through our epilepsy page by presenting cases, videos and articles. This act as a form of continuous medical education to the members and doctors whom deal directly or indirectly with epilepsy in the medical health service. Dr Hassan Hosny and Dr Chahnez Triki are members in the page.

During 2018 we held our first epilepsy chapter symposium

on Saturday 13/10/2018 for one day and the programme has been posted in the ILAE region page, this symposium considered to be successful.

Challenges:

The country still has political instability and insecurity, as well as continuing financial difficulties.

Future Plans:

Epilepsy symposium next year

Officer Election Date: Next year

MALAYSIA: Malaysian Society of Neurosciences

Report By: Loh Hui Pin, MSN Epilepsy Council Secretariat

Summary of Activities:

1. Publishing guidelines and recommendations on epilepsy
2. Organising professional meetings and conference on epilepsy
3. Constructing curriculum for postgraduate training in epileptology
4. Accrediting epilepsy centres for postgraduate training in epileptology
5. Recognising or certifying specialists in epileptology
6. Advising the Government on epilepsy and epilepsy-related issues
7. Initiating and coordinating research related to epilepsy to collaborate with MES and other organizations on related epilepsy issues

Details of activities 2018-2019:

1. 3rd Epilepsy Teaching Course

The 3rd Epilepsy teaching course was recently held at the Sarawak General Hospital, Kuching from 8th to 9th September 2018. This event was organised by the Epilepsy Council of the Malaysian Society of Neurosciences (MSN) and ANZAN and was supported by the Global Campaign Task Force of the Commission on Asian and Oceanian Affairs (CAOA) for the International League Against Epilepsy (ILAE). The course format was adapted from the ASEPA Summer School course and we were honoured to

Chapter Reports *(continued)*

have Professor Ernest Somerville and Prof John Dunne from Australia as guest speaker and lead facilitators during the 2 days. Topics covered included differential diagnosis of epilepsy, classification of seizures and epilepsy, management of epilepsy in general and in special situations, as well as cultural aspects of epilepsy. A total of 90 participants, the majority of whom were from East Malaysia, attended this 2-day course. East Malaysia has the highest treatment gap in the country. The participants thoroughly enjoyed the course, citing in particular, the interactive sessions and discussion with the speakers and facilitators as well as relevance of the topics discussed as strengths of the course. Overall, the course was a success.

Course Faculty:

Ernest SOMERVILLE (Director) Prince of Wales Hospital, Sydney, Australia

John DUNNE Royal Perth Hospital, Perth, Australia

Raymond AZMAN ALI National University of Malaysia, Kuala Lumpur, Malaysia

Sherrini Ahmad BAZIR AHMAD Sime Darby Medical Centre, Subang Jaya, Malaysia

Kheng-Seang LIM University of Malaya, Kuala Lumpur, Malaysia

Choong Yi FONG University of Malaya, Kuala Lumpur, Malaysia

Wan Chung LAW Sarawak General Hospital, Kuching, Malaysia

Yuen Kang CHIA Queen Elizabeth Hospital, Kota Kinabalu, Malaysia

Recruitment of New Council Members

Total of 5 new council members were recruited:

1. Dr Sulaila Basiam – Hospital Tuanku Ampuan Afzan
2. Dr Hana Maizuliana Solehan – University Science Islam Malaysia
3. Dr Mazlina Husin – Hospital Tuanku Ampuan Afzan
4. Dr Jayaganth Jayabal – KPJ Sungai Petani
5. Dr Farooq Shaikh – Monash University Malaysia

Series of CMEs

Prof. Dato' Dr. Raymond Azman Ali – Talks in 2018

1. Delivered a lecture titled Optimising Treatment Approach to Focal Seizures – the clinician's perspective, DKSH Headquarters, Kelana Jaya, Selangor, Malaysia, 16 January 2018.
2. Delivered a lecture titled Challenges in the Treatment of Refractory Epilepsy and Why New AEDs are required at the Eisai Fycompa Experts Sharing Meeting, Le Meridien Hotel, Kuala Lumpur, Malaysia, 20 January 2018.
3. Delivered a lecture titled Introduction to the Epilepsy Council, Malaysian Society of Neurosciences at the CURE seminar, Monash University, Sunway Campus, 28 February 2018.
4. Delivered 2 lectures titled Seizures: It is Not Always Epilepsy and Challenges in the Treatment of Refractory Epilepsy and Why New AEDs are required at the Neurology Update 2018, Hospital Raja Permaisuri Bainun, Ipoh, Perak, 31 March 2018.
5. Delivered a lecture titled Optimising Treatment Approach in Focal Seizures at the Neurology Department CME, Sarawak General Hospital, Kuching, Sarawak, 27 April 2018.
6. Delivered 2 lectures titled Seizure Semiology: The Study of the Signs of Epilepsy and Update on the Pharmacological Treatment of Epilepsy at the East Coast Epilepsy Update, Kuala Terengganu Specialist Hospital, Kuala Terengganu, Terengganu, 11 July 2018.
8. Delivered a lecture entitled Optimising Treatment Approach in Focal Seizures at the Hospital CME of Queen Elizabeth Hospital, Kota Kinabalu, Sabah, 20 July 2018.
9. Delivered a lecture entitled Fits, Faints and Funny Turns at the AOMC-MSN PreCongress Workshop themed Essential Neurology for Nurses and Paramedics, UKM Medical Centre, Kuala Lumpur, 26 July 2018.
10. Delivered a lecture entitled Is it Epilepsy? At the 17th AOMC & 28th MSN Annual Scientific Meeting, Istana Hotel, Kuala Lumpur, 28 July 2018.

Chapter Reports *(continued)*

11. Delivered a lecture entitled Management of Epilepsy in the 21st Century at the 32nd Scientific Meeting of the Malaysian Society of Pharmacology and Physiology, Hotel Bangi-Putrajaya, Selangor, Malaysia, 8-9 August 2018.
12. Delivered a lecture entitled Optimising Treatment Approach in Focal Seizures at the Department of Medicine CME, Penang Hospital, Malaysia, 9 August 2018.
13. Delivered a lecture entitled Fits, Faints and Funny Turns at the Neurology Workshop themed Understanding the Brain and Mind, organised by the Neurology Unit, Department of Medicine, UKM Medical Centre, 11 August 2018.
14. Delivered a lecture entitled Optimising Treatment Approach in Focal Seizures at the Department of Neurology CME, Hospital Tuanku Ampuan Afzan, Kuantan, Malaysia, 14 August 2018.
15. Delivered a lecture entitled Update on the 2017 Malaysian Epilepsy Consensus Guidelines at the Parkinson Disease and Epilepsy Workshop, Hospital Raja Permaisuri Zainab II, 6 September 2018.
16. Delivered a lecture entitled Is it Epilepsy? at the 3rd Epilepsy Teaching Course organised by the Epilepsy Council, Malaysian Society of Neurosciences, Sarawak General Hospital, Kuching, 8 September 2018.
17. Delivered a lecture entitled Optimising Treatment Approach in Focal Seizures at the Department of Medicine CME, Hospital Tuanku Jaafar, Seremban, Malaysia, 11 October 2018.
18. Delivered a lecture entitled Seizures: It is Not Always Epilepsy at the CME of the Medical Faculty, Asia Metropolitan University, Muar Campus, Johor, 31 October 2018.

MALTA: Malta Epilepsy Society

Report By: Janet Mifsud

Publications:

Toolkit in Maltese and English in collaboration with Caritas Malta Epilepsy Association

Summary of Activities:

- Liaison with the Caritas Malta Epilepsy Association in the organisation and contribution of talks during the National Epilepsy Conference 2017 10 March 2018 Epilepsy: Finding Help
- Liaison with the Caritas Malta Epilepsy Association in outreach and media activities and public talks
- Participation in international epilepsy meetings

Challenges:

Small number of members

Future Plans:

Ongoing improvement of epilepsy services for adults and children with epilepsy

Officer Election Date: 2020

MEXICO: Mexican League Against Epilepsy

CAMELICE; Capitulo Mexicano de la Liga internacional Contra La Epilepsia.

Report By: Daniel San Juan Orta, Secretary

Publications

- Spanish translation of slide of seizure ILAE Classification, 2017.
- Seizure sheet for patients in Spanish

Summary of Activities

- Joint Symposium of epilepsy and cannabis in XLII Annual Meeting of Mexican Academy of Neurology 2018, 5-11 November, Merida, Mexico.
- Joint and support the X Latino-American Meeting in Epilepsy 29 September to 2 October 2018, San José Costa Rica.
- Incorporated the ILAE Young Epilepsy Section on 27 August 2018.

Chapter Reports *(continued)*

- Co-chair the IX International Symposium of Epilepsy and Epilepsy Surgery, 1-3 February 2018. Sevilla, Spain.
- Organized the XL National Annual Meeting joined to the Northeast Meeting supported by the Mexican Priority Program of Epilepsy, 26-27 July 2017. Tijuana, Mexico.
- Signed a Pacto Nacional de Buena Voluntad between CAMELICE and the Mexican Association of Epilepsy in Children and Adults, 23 March, 2017, Mexico City, Mexico. TV declaration.
- Promoting the Purple Day, 2017 in newspapers, aka: <http://www.milenio.com/estados/vivir-con-epilepsia-el-camino-del-estigma-al-mejor-tratamiento>

Challenges

Get financial support for future meetings, promote the educational opportunities abroad for the members, increase the research awareness of research in epilepsy in our country, get the access to all the diagnostic and treatment available in epilepsy for our patients and members.

Future Plans

Organized the XLI National Annual Meeting, Mazatlán, Sinaloa, Mexico, 28 to 31 of august 2019.

Officer Election Date: October 2018

MONGOLIA: Mongolian Epilepsy Society

Report By: A.Tovuudorj

Publications:

1. Amarjargal M., Tovuuudorj A., Study of memory impairment in temporal lobe epilepsy. The 5th Annual meeting of the Mongolian neuroscience society 2018, UB p 40
2. Amarjargal M., Tsagaankhuu G.,Tovuudorj A. Clinical characteristics of mesial temporal Lobe epilepsy with hippocampal sclerosis and temporal lobe epilepsies due to other etiologies. CAJMS, Ulaanbaatar, 2017 November; 6 (6) 311-317.

Summary of Activities:

In 2002, the academic cooperation between Mongolian Epilepsy Society and Mongolian National University of Medical Sciences and Commission of Asian Ocean Affairs

was established. Since that time, ILAE-Asia Oceania and ASEPA have done many of the effective work and training toward enhancing the health care of Mongolian patients with epilepsy and sharing the knowledge on advanced methods and experiences of epilepsy diagnosis, treatment and care.

The International Epilepsy Symposium has been organized by Department of Neurology, Mongolian Epilepsy Society once in every 2 years, since 2012. The Mongolian Epilepsy Society and Association are actively promoting educational activities on epilepsy to improve quality of life of affected people. These activities help people with epilepsy and their family members by improving access to health care services and preventing stigma and discrimination.

Epilepsy care in Mongolia has been improving steadily in the recent years, but there are still gaps that need to be addressed. We need to strengthen the capacity of health care workers, especially in rural areas; provide necessary equipment for diagnosis of epilepsy and ensure adequate supply of essential medicines, especially for the poor and disadvantaged people. Improving families' and communities' knowledge and attitude on management of epilepsy is also very important.

We have successfully organized the ASEPA EEG and Epilepsy and Ketogenic workshops in September of 2018 in Ulaanbaatar.

Challenges:

5th International epilepsy symposium - July 2020, Ulaanbaatar.

Future Plans:

- To establish the National epilepsy center of Mongolia and improve the epilepsy care of patients with epilepsy;
- To train and prepare qualified epilepsy professionals (adult epileptologists, pediatric epileptologists and pediatric neurosurgeon) EEG technician and epilepsy staff nurses;
 - To get the necessary medical equipment and tools for diagnosis and treatment;
 - To broadly introduce the new antiepileptic drugs, epilepsy surgery and other methods of epilepsy treatment;
 - To implement pediatric epilepsy surgery program;

Chapter Reports *(continued)*

- To cooperate workshop and symposium on epilepsy;
- To conduct brief time exchange program and;
- To invite visiting professor for improving epilepsy care in Mongolia etc.,

Officer Election Date: September 2020

MYANMAR: Epilepsy Special Interest Group of Myanmar

Report By: Nyan Tun

Publications:

- Poster presentation on ketogenic therapies for neurological disorder by Paediatric neurology team at 6th global symposium in October 2018
- Initiation of ketogenic diet service in Myanmar and challenges by Chaw Su Hlaing
- Knowledge and attitude towards ketogenic diet among Myanmar pediatric trainees by Aye Mya Min Aye
- Three children with drug resistant epilepsy for the first ketogenic diet in Myanmar by Hnin Wint Wint Aung

Summary of Activities:

- Chapter meetings twice a year and annual meeting in December
- CME activities in Yangon, Mandalay and other townships 2-3 times a year respectively
- Provide technical assistance and participate in the activities of Myanmar Epilepsy Initiative (MEI Project)

Activities (2017) in MEI Project

- HE talks for raising community awareness about Epilepsy in Nyanung Lebin and Pantanaw Townships
- Training (2 new townships) and refresher (old 5 townships) for Medical Officers (MOs), General Practitioners (GPs), Basic Health Staff (BHS) and Voluntary Health Workers (VHW)
- Epilepsy ToTS for future trainers, Yangon
- Activities (2018) in Myanmar Epilepsy Initiative (Project)
- International Epilepsy Day: Mawlamyine, Mon State (February 2018)

- Purple Day: to promote epilepsy awareness, in March 2018, at Yangon Children's Hospital
- Epilepsy ToTS for future trainers of State/Region, in Yangon and ToTS for MO trainers and BHS trainers from new scaling up 8 townships in Mawlamyine, Mon State
- Supervise in Epilepsy training for Health care providers (HCP) of new scaling up 8 townships

Activities of Paediatric team

- Managing epilepsy children in Outreach Neurologic clinics at Insein general hospital, Yankin Children Hospital and Kyike Wine School for children with special needs in Yangon every month and in 4 other cities: Bago, Patheingyi, Mawlamyaing, Magway civil hospitals every 3 months yearly
- International Pediatric Epilepsy Training (iPET) courses in Yangon, Mandalay and Magway under collaboration with British Pediatric Neurology Association (BPNA)
- With the collaboration between Myanmar pediatric neurologists and Korean Epilepsy Society (KES), the first Paediatric Epilepsy and Ketogenic diet workshop was held at Yangon Children Hospital in March 2018.
- Develop Ketogenic center of Myanmar at Yangon Children hospital in late 2018

Challenges:

- To promote public awareness on Epilepsy
- To provide community-based approach Epilepsy treatment services at primary health care
- To reduce treatment gap and promote Quality of Life among people with epilepsy

Future Plans:

- The International Epilepsy Day will be held in Kayin State.
- To launch new scaling-up MEI programme in all respective townships of Kayin and Kayah States simultaneously

Officer Election Date: tentatively in third week of December 2019

Chapter Reports *(continued)*

NEPAL: Nepal Epilepsy Society

Report By: Prabin Shrestha, MD, PhD, General Secretary

Publications:

Frequent publication of public awareness materials, pamphlets etc. No Journal.

Summary of Activities:

- a. Free epilepsy camps to remote areas of the country 4 times a year
- b. Epilepsy awareness programs
- c. CMEs by epilepsy practitioners

Challenges:

- a. Financial limitations
- b. Lack of formal office and office secretary
- c. Lack of enthusiasm in society members
- d. Less no of active members

Future Plans:

- a. Increase the number of members
- b. Increase the activities
- c. Organizing epilepsy camps and CMEs more frequently

Officer Election Date: September of 2020

NETHERLANDS: Dutch League Against Epilepsy

Report By: Dr. R. Rouhl

Publications:

Epilepsie, periodiek voor professionals (4 times yearly, in Dutch, sent to all members of the Dutch League)

Summary of Activities:

- + Outreach to the minister of health for adjustments in the reimbursement of vagal nerve stimulators
- + Startup of the epilepsy network, a collaboration in epilepsy care and education between epilepsy specialist centers and general hospitals
- + Authorization of option grids and epilepsy guidelines

- + Support letter for application for reimbursement of deep brain stimulation in refractory epilepsy
- + Organization of National Epilepsy Symposium (November 2018)
- + Organization of two sessions of the scientific section of the Dutch League (February 2017, March 2018)
- + Coordination of communication on negative effects of valproate in pregnancy (and consequences for guidelines and surveillance)
- + Annual update of web-based national epilepsy guidelines
- + Start of a pilot in training on guideline development for residents in neurology
- + Kick off European Partnership on Competencies for High Value COst CONscious CARE: European training in guideline development

Challenges:

Ensure the sustainability of the epilepsy network with its associated knowledge dissemination

Future Plans:

- + Co-organize one of the ILAE Congresses (ECE)
- + Continuing education and dissemination of knowledge for all epilepsy professionals by our publications and conferences (yearly SWO meeting and every second year in the National Epilepsy Symposium)

Officer Election Date: yearly vacancies (not bound to terms)

NEW ZEALAND: New Zealand League Against Epilepsy

Report By: Lynette Sadleir

Publications:

Epilepsy Guidelines and Pathways for New Zealand Children and Young People <https://www.starship.org.nz/guidelines/epilepsy-guidelines-and-pathways-for-children-and-young-people/>

Summary of Activities:

We are fortunate to have a great group of clinicians in New Zealand who are committed to improving the management of epilepsy for New Zealanders. Through volunteered time they have educated, informed, advocated, administrated

Chapter Reports *(continued)*

and networked to help achieve this goal. Our members have worked on several national committees including the Ministry of Health Epilepsy National Improvement Project and the Paediatric Neurology Clinical Network. 2017 and 2018 were busy and productive years for the New Zealand League Against Epilepsy (NZLAE).

In 2018 we adopted a logo. The design was inspired by several elements. At the beginning of the spiral is a lightning bolt representing abnormal brain activity in a seizure. The end of the spiral has a Koru on it representing New Zealand and the hope for a cure.

Activities undertaken by the NZLAE in 2017 & 2018 include:

Education

NZLAE Educational Day Oct 19, 2018 Christchurch

“Seizures: Clinical Manifestations and Diagnosis”

International Guest Speaker Professor Patrick Chauvel

This meeting was held in the South Island for the first time and we also held an inaugural meeting for Epilepsy Nurses as a satellite symposium.

Paediatric Epilepsy Training Courses

In 2017 the NZLAE introduced the British Paediatric Neurology Association Paediatric Epilepsy Training (PET) Courses to New Zealand. Our aim is for all paediatricians involved in the care of children with epilepsy to complete PET 1, 2 and 3 courses every five years and for any physician and allied health professional who encounters children with epilepsy, be it in general practice, ED, the EEG department or the community, to do a PET 1 course every five years. With the help of the BPNA our local paediatric neurologists were trained on course delivery and the first course was conducted in March 2017. Over the last 2 years we have delivered five PET 1 courses, three PET 2 courses and one PET 3 course. The courses are extremely well received and oversubscribed. We have had over 170 New Zealand clinicians, mainly paediatricians, attend these courses.

Improvement of Epilepsy Care:

After extensive consultation with the New Zealand Paediatric Neurology and Paediatric communities,

Epilepsy Guidelines and Pathways for New Zealand Children and Young People were developed and are now published on the New Zealand Paediatric Clinical Network website. These guidelines are aimed at paediatricians and were introduced in combination with the PET courses. We have also updated all other New Zealand epilepsy health resources for both physicians and families so that the content aligns with our new guidelines. We have developed multiple information sheets and web based resources on seizure and epilepsy topics for paediatricians to use with families including an Epilepsy Passport. Our aim is that all New Zealand guidelines, pathways and information for people with epilepsy will be up to date, evidence based and aligned with expert epileptology consensus. It is envisioned these initiatives will facilitate improved care for New Zealand children and young people with epilepsy.

Communication:

To communicate information from both the NZLAE and ILAE to our members we have initiated a 4 monthly newsletter.

Challenges:

As a small country we have a small number of paediatric and adult neurologists with an interest in epilepsy. These individuals are busy and already stretched with their clinical and research workloads. They generously volunteer their time to undertake NZLAE activities, but our progress is limited by time available. It is important for us to use their time and expertise wisely and efficiently. Unfortunately, we do not have financial resources to fund administrative support. This is particularly an issue with the delivery of the PET courses. We are hopeful that the Australian and New Zealand Child Neurology Society will introduce PET courses to Australia in 2019 as this will increase available faculty for our Australasia region and funding for administration.

Future Plans:

In 2019 we will continue to deliver PET courses and our annual educational meeting. We will work to coordinate and advocate for the implementation of our guidelines throughout the countries 21 District Health Boards. We have started to develop Health Pathways for family doctors which will feed into our paediatric guidelines.

Chapter Reports *(continued)*

Officer Election Date: Nov 2019

NORTH MACEDONIA: League Against Epilepsy of Republic of Macedonia

Report By: Emilija Cvetkovska

Publications:

Epilepsy and Neurology

Summary of Activities:

Educational Seminars and workshops on new seizure and epilepsy classification and pharmacological treatment of epilepsy.

Community activities at Purple Day

Challenges:

Development of Epilepsy surgery program

Future Plans:

Continue educational activities

Officer Election Date: 2020

NORWAY: Norwegian League Against Epilepsy

Report By: Cecilie Johannessen Landmark, PhD, Professor, Vice President; and Erik Sætre, MD, PhD, President

Members of the board

The board from 2017 to 2018 (academic year) was constituted at the annual meeting and included: President Oliver Henning; Vice President: Cecilie Landmark Johannessen; Secretary: Anne-Karin Hagen; Treasurer: Marte Bjørk, and web-manager: Silje Alvestad.

Other members: Thorsten Gerstner; Ann- Kathrin S. Munkeby; Sigrid Svalheim; Bjørnar Hassel; Tine Pape; Christian Samsonsen.

The board was balanced between gender, background, and geographically to various health regions and university hospitals.

The Annual meeting 2018

About 100 delegates participated at the annual meeting in Trondheim, May 2018. There was a broad programme with plenary lectures, specialized topics, inter-disciplinary approaches and regional distribution. Invited guest lecturer was Professor Marco Mula, UK. A new part from 2017 of the programme was open presentations, for young scientists to present their ongoing research. 10 abstracts had been submitted and presented, a winner was rewarded, and three were given reimbursement for the next meeting. The meeting was ended by the annual formal meeting and information from the Norwegian Epilepsy Association, the patients' association. The social programme included an evening tour to the nearby old monastery on an island, and a tour around the arch bishop's castle nearby the famous cathedral Nidarosdomen.

The Annual Neurological days 2018

This week is organised by the Norwegian Neurological Association in mid-March, with 1-2 days including a programme related to epilepsy. In addition, an evening symposium was arranged on differential diagnostics and semiology of epileptic seizures.

Collaboration and networking

Our chapter has collaboration with the other Scandinavian chapters of ILAE regarding the translation of the new seizure classification during spring 2017. The Norwegian translation resulted in to publications in the Norwegian Journal of the Medical Association, by Oliver Henning et al. during autumn 2017.

The International Epilepsy Day 12.02.2018 was marked by an arrangement in collaboration with the Norwegian Epilepsy Association (Patients' organization), where central persons from around the country and patients and their representatives gathered to debate on challenges regarding information and spreading information to all groups, and how these challenges may be overcome.

Cecilie Johannessen Landmark represented the Norwegian chapter at the ILAE-meeting at the International epilepsy congress in Barcelona in September.

Economy

The annual report was presented at the annual meeting.

Chapter Reports *(continued)*

Board meetings

Three board meetings have taken place during this period.

OMAN: Oman League Against Epilepsy

Report By: Dr Nabil Al Macki

Summary of Activities:

- Regular CME activities in topics related to Epilepsy
- Public activities to increase the awareness about epilepsy

Challenges:

To introduce epilepsy surgery locally

Future Plans:

- To introduce epilepsy surgery locally
- Increase ketogenic centers

Officer Election Date: Next year

PARAGUAY: Paraguayan League Against Epilepsy

Report By: Silvia Abente

Summary of Activities:

- Primary Care in Epilepsy courses
- Active participation in EEG Telemedicine government program
- Family and patient encounters in the hall of patients
- Guidance to patients and support by consultancy

Challenges:

- To reach more involvement from the government to apiece the Epilepsy Program in a national level.
- The Epilepsy Law

Future Plans:

- Epilepsy week: an encounter from all specialist and general physicians interested in Epilepsy. ALADE course 2019 in Asunción
- Primary Care in Epilepsy new 2019 edition
- First EEG course to technicians

- Publication to the validation of the Detection scale for Epilepsy in Primary Care questionnaire in Guarani

Officer Election Date: May 2019

PHILIPPINES: Philippine League Against Epilepsy

Report By: Mel Michel Villaluz

Summary of Activities:

MEETINGS, 2017

1st Philippine League Against Epilepsy – Child Neurology Society Joint Symposium on Status Epilepticus and 9th PLAE National Epilepsy Congress

- July 17-19, 2017; Marco Polo Hotel, Cebu; Number of attendees: 381
- The three-day conference discussed the current and relevant issues in epilepsy including Status Epilepticus - lectures on definitions, classification, diagnosis, treatment, prognosis and panel discussion on treatment of SE in the region; Neurobiology of AEDs, the New ILAE classification of seizure types and epilepsies, adolescent issues in epilepsy.

2017 PLAE Postgraduate course: Epilepsy in tropical infectious diseases / Mental health gap workshop

- September 28, 2017; Marco Polo Hotel, Ortigas; Number of attendees: 125
- The postgraduate course discussed the development of epilepsy in association with the common infectious diseases encountered in the country, namely bacterial and tuberculous meningitis, neurocysticercosis, and HIV infection. The afternoon session was a special meeting for the PLAE members introducing the epilepsy module that will be utilized by the Department of Health for training the rural health workers in recognizing seizure types and basics of epilepsy management in a community-based healthcare setting.

ACTIVITIES in Relation to Global Campaign, 2017/2018
“Beyond the Shake” Multimedia Campaign

The “Beyond the Shake” Epilepsy Awareness campaign was initiated Dr. Ana Javelosa (PLAE President, 2016-2017).

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This is PLAE's response to revitalize the Global Campaign of bringing epilepsy out of the shadows by using social media for information dissemination. Using the Facebook social media platform, the awareness campaign was conducted regularly via providing infographics on the facts and fallacies about epilepsy. Instructional videos on first aid for seizures were featured in the platform and in select movie theaters. Billboard ads were utilized to promote the campaign.

In 2018, the campaign was again promoted during the county's annual National Epilepsy Awareness Week. This is held during every first week of September since 2001. This year LED billboards in the main thoroughfares were utilized to promote the epilepsy awareness using the motto: "Cease the Seizure."

Moreover, PLAE volunteer doctors started to hold epilepsy lay fora in the shopping malls with the aim to put epilepsy in the mainstream public awareness. The 1st event was done during the March 26, 2017, World Purple Day, wherein events were held simultaneously in three (3) main malls of the country's main islands. An Epilepsy summit was held on September 7, 2018 in one of the main malls of Metro Manila in celebrating this year's National Epilepsy Awareness week. Moreover, multiple short lay fora were held in the different hospitals during this period.

National Epilepsy Camp:

In 2018, the 7th National Epilepsy Camp was held in Miagao, Ilo-Ilo. This biennial activity aims to promote improved health care delivery services and quality of life through educating family members, teachers, primary caregivers and rural health workers on epilepsy. There were 431 attendees during this year's camp.

Epilepsy School Caravan

In 2009, a teaching module on epilepsy for children in the grade schools was developed by Dr Marilyn Ortiz and Dr. Lourdes Ledesma. The "Happy-Lepsey" jingle was developed to promote a positive outlook for persons with epilepsy. In 2016, the book characters, Epi and Lepsey, were made into mascots to be more engaging for the children during activities.

The objective of this project is to promote epilepsy awareness

among children and school teachers with the hope that one day, patients with epilepsy will no longer be discriminated in school. Teachers and students are also taught first aid in handling acute seizures. Since its conception, over a hundred epilepsy caravans have been conducted in public and private schools all over the Philippines.

In July 2018, PLAE has entered a five (5) year partnership with the Bulilit Health Worker Program under the Philippine Medical Association, wherein the Epilepsy module now included in their 5-week national health awareness course for Grades 5 and 6 students.

Epilepsy Manager Program

The Epilepsy Manager Program was started in 2002. It is the brainchild of Dr. Ma. Felicidad Soto, who conceptualized it in response to the glaring lack of specialists or doctors trained to handle epilepsy in the countryside. Its objective is to make available to all Filipino people a doctor who is competent in managing persons with epilepsy at the primary care level, located within a one-hour bus ride of their home. This 10-month training program for general practitioners, private or government doctors include an intensive 2-day didactics on epilepsy, establishing an epilepsy clinic in the community, monthly visits from 2 PLAE doctor volunteers to check on the doctors' progress in handling epilepsy cases and to give further training and a final culminating evaluation. Once completed, the doctor /epilepsy manager is endorsed to the supervision of the nearest neurologist in the region.

In 2017, PLAE volunteers were able to complete the training of six (6) municipal and provincial health workers in the province of Antique.

The Philippine Mental Health Act

In June 2018, RA 11036 was signed into law. This landmark legislation will guarantee access to comprehensive and integrated mental health services, and it ensures protection and the promotion of the rights of persons with psychiatric, neurologic and psychosocial health needs as well as their families. Through the efforts of Dr. Leonor Cabral-Lim (PLAE Past President, 2001-2006), several neurological disorders, especially epilepsy, were included in the expansion and improvement of health care delivery as stated in the law. This will greatly benefit persons with epilepsy and their families as this entail access to comprehensive and

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integrated mental and neurological health services from the community level up to tertiary hospital level.

Challenges:

Presently, PLAE will continually collaborate with the Department of Health in improving the quality of health care services for persons with epilepsy through education programs for the primary caregivers.

Future Plans 2019:

1. 10th National Epilepsy Congress, September 26-28, 2019, The Manila Hotel
Theme: Epilepsy Across the Ages: Advancing the science, improving the care
2. Update on the Status Epilepticus Local Guidelines.

Officer Election Date: September 2019

POLAND: Polish Society of Epileptology

Report By: Grabowska Albena

Publications:

Educational Books (in Polish) for neurologists, GP, psychiatrists, neuropsychiatrists:

- “Epilepsy – semiology of epileptic seizures” (2017)
- “Epilepsy – etiology” (2018)
- “Convulsive status epilepticus management in adults and children: Report of the Working Group of the Polish Society of Epileptology”. Jędrzejczak J, Mazurkiewicz-Będzzińska M, Szmuda M, Majkowska-Zwolińska B, Steinborn B, Ryglewicz D, Owczuk R, Bartkowska-Śniatkowska A, Widera E, Rejda K, Siemiński M, Nagańska E. *Neurol Neurochir Pol.* 2018 Aug;52(4):419-426. doi: 10.1016/j.pjnns.2018.04.002. Epub 2018 Jun 13.
- Managing epilepsy in woman of childbearing age – Polish Society Of epileptology and Polish Gynecological Society Guidelines. Jędrzejczak J, Bomba-Opoń D, Jakiel G, Kwaśniewska A, Mirowska-Guzel D. *Ginekol Pol.* 2017;88(5):278-284. doi: 10.5603/GP.a2017.00

Summary of Activities:

Meetings:

In 2017 XXVIII Conference on Epilepsy organized by Polish Society of Epileptology, Warsaw 05, 400 participants.

In 2018 VIII Congress on Epilepsy organized by Polish Society of Epileptology, Warsaw 05; 400 participants.

The national experts on various fields of epilepsy were invited to give lectures. The topics covered were: epilepsy and pregnancy, video-EEG diagnostic values in different types of epileptic syndromes and non-epileptic events. We discussed the differential diagnostic difficulties, EEG patterns in different stages of consciousness. Important topics covered angiogenic etiology of epileptic seizures and different aspects of post-stroke epilepsy as well as sleep disturbances in patient with epilepsy, and movement episodes differential diagnosis.

During last year we have introduced especially addressed to our young participants 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 satellite symposium we talked about the important theme as personalized medicine in epilepsy. In panel discussion we considered the need for individualized treatment in patients with epilepsy. We presented also usefulness of genetics in diagnosis of epilepsy. Discussion convened by the Polish Society of Epileptology, focused on medical and social aspects of epilepsy namely daily problems for patients with epilepsy, their needs and limitations. Many public lectures and discussion group meeting have been organized with neurologists - public health awareness. Organization forum for key opinion leaders across medicine, government, and health systems.

Many aspects of 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, remains very important topic of many meetings. We have prepared in cooperation with Polish Society of Gynecologists standards for management with women with epilepsy in reproductive age. The letter on the subject was send to Polish Ministry of Health.

Polish Society of Epileptology with Child Neurology Society presented their opinion according using marihuana in the

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treatment of epilepsy pointing the need of reliable studies.

Summary of Activities in Relation to Global Campaign in 2017 and 2018

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 the form of happening in Warsaw.

An important part of our activities in 2017 and 2018 are contacts with the Ministry of Health and National Health Fund. Main problem is the reimbursement for patients of new AEDs in epilepsy. Finally, levetiracetam, oxcarbazepine is free for patients in newly diagnosed (I line) epilepsy, lacosamide is free for patients with III line of treatment epilepsy.

Preparation research paper 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 different fields of their life.

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 errors in communication patient-neurologist using presented by actors and recorded scenes. Scenario was prepared by epileptologists 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 exist 14 organizations of patients (nine of them are district chapters of Polish People Suffering from Epilepsy established in 1985). Cooperation with web site "the same as me" devoted to patients with epilepsy as forum and information prepared by neurologists.

Challenges:

The discussion on the scheme of pharmacological treatment of new onset and drug resistant epilepsy in Poland - we plan to change the place of lacosamide to the second line treatment drug. We plan to discuss the position of Stiripentol in Dravet syndrome and Epidiolex in Dravet and Lennox-Gastaut syndromes and local rules of reimbursement of the new antiepileptic drugs.

Future Plans:

To continue the regular educational courses. To elaborate the new standards of the quality control, to the epilepsy care in Poland. We have prepared with Polish Neurological Society the project of National Guideline of diagnosis of epilepsy in adult and children.

We plan to update the recommendations from 2014 for the treatment of new onset and drug resistant epilepsy in Poland.

We plan to organize the Conference on Different aspects of total care of the patients with psychogenic non-epileptic seizures. The national experts on various fields of epilepsy, psychiatry and psychology are invited to give lectures.

Officer Election Date: 2022

ROMANIA: Romanian Society Against Epilepsy

Report By: Tarta Arsene Oana, Secretary

Summary of Activities:

2017

- 13 Feb 2017 - International Epilepsy Day -- we posted on Facebook and on the Romanian Society Against Epilepsy (SRIE) website – two messages – do you know what to do in a seizure (link) and Do you know what epilepsy is?
- 26 March 2017 - Purple Day Supporting Epilepsy Around the World
 - o Several public buildings in Bucharest were lighted in purple (Romanian Atheneum, Fountains from the City Center, Parliament Palace)
 - o Purple bicycle tour for epilepsy', city center of Bucharest for awareness of epilepsy was organized

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- o together with the Dravet Association, Romanian Foundation for Neurology and Epileptology, Scientific Students Association and Cyclism Association Bucharest (Pediatric Neurologists and Neurologists with interest in epilepsy, patients and their families, press persons, students and a cyclism association participated);
- o Salsa event for awareness of Epilepsy - common action with, Dravet and other rare epilepsies association'
- ♦ 14-18 Nov 2017 The XXVth Annual SRIE Conference (<http://ilae-romania.ro/conferinta-srie-editia-a-xxv-a>)
 - o 14 Nov. 2017 Curs preconferinta Epilepsia prin cazuri clinice (Preconference course Epilepsy hands on) - invited speaker Walter van Emde Boas
 - o 15-16 Nov -2017. Conference - invitated speakers Walter van Emde Boas, Dragoslav Sokic, Dorota Hoffman-Zacharska , Sandor Beniczky, Anna Kelemen, Aleksandar Ristic, Stefano Francione , Kees Braun , Petia Dimova
 - o 17 Nov. 2017. Course: Investigating resistant epilepsy (invited speakers: Kees Braun, Dragoslav Sokic, Aleksandar Ristic, Petia Dimova, Lorella Minotti, Philippe Kahane, Stefano Francione, Carmen Barba)
 - o 17-18 Nov 2017: U-Task Meeting was held in Bucharest
 - o 18 Nov 2017: Scientific Meeting SRIE- Dravet Association. Parents and doctors met and discussed different issues as the Emergency protocol and personalized Letter, Dravet practice protocol, Vaccination in Dravet Syndrome

2018

- ♦ 14th February 2018 – International Day of Epilepsy
 - o Video with first-aid for epileptic seizure – for general population, it was uploaded to social sites) <https://www.youtube.com/watch?v=mKs12vlvR0>
 - o Together with the students from SOMS (Scientific Society of Students from Bucharest University of Medicine) – we translated the video from WHO “What epilepsy is”) <https://www.youtube.com/watch?v=WuhKe004KLY&t=87s>
 - o TV space on the epilepsy day – “Do you know what to do in epilepsy?” – discussion about epilepsy in the world and in Romania: <https://www.youtube.com/watch?v=zfI0d-MpNuA>

- ♦ 26 March 2018 - Purple Day Supporting Epilepsy Around the World
- o Several public buildings in Bucharest were lighted in purple (Romanian Atheneum, Fountains from the City Center, Parliament Palace)
- o Salsa event for awareness of Epilepsy - common action with, Dravet and other rare epilepsies association'
- o 11-13 iulie 2018- Summer School Sucevita- A practical course for Epilepsy: invited speakers (Nebosja Jovic, Luca de Palma, Trevisano Marina, Petr Marusic).
- o 4-6 Oct 2018 The XXVIth Annual SRIE Conference – Cluj-Napoca
- o 4 Oct Course Basic EEG Preconference course Epilepsy hands on) - invited speaker Dr Walter van Emde Boas. This course was organized for nurses working in the EEG field. Although the initial target was to train 50 nurses, around 110 popped up and stayed for the whole duration of the course. Practical work on manikins and on EEG machines followed the theoretical presentations.
- o 4 Oct Course New Classification of Epilepsies – invited speaker Dr Walter Van Emde Boas. We discussed the new 2017 classification of seizures and of epilepsies based on clinical cases, in an interactive manner
- o 5-6 Oct SRIE The XXVIth Annual SRIE Conference. YES Romania (Young epilepsy section) was created with the occasion of this Conference. Also the nurses organized themselves in what it is called SAM-RO (Nurses section of SRIE) aiming further training and specialization concerning epilepsy and EEG.

Future Plans:

- ♦ Transition meeting 7 Feb 2019. This is a very important meeting for Romania, which is at the beginning of UE leadership; we try to take action in one of the “hot” issues in health today – how to organize transition from children to adults and to create a model to be adopted by people working in Eastern Europe with the help of the leaders in epilepsy. Leaders from Bulgaria, Serbia, Croatia, Republic of Moldova and Romania will participate in order to identify the main problems related to transition. The ILAE-Europe President, Eugen Trinka; Hellen Cross,

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member of the Executive Committee of the ILAE, are two of the participants who will guide a Transition Protocol development for epilepsy patients

- 26 March 2019 - militate for purple illumination of public buildings in Bucharest
- 26 March 2019 - common action with Dravet and other rare epilepsies association - Raising awareness on epilepsy
- 26 March 2019 - common action with Cyclists association - Bucharest Marsh on bicycle for epilepsy day
- Finalise Syllabus for EEG technicians and obtain recognition from the Ministry of Health, Romania
- SRIE Summer school in Association SRIE- ASNER (Neurophysiology association) will join the organization of the 5th East European Course of Epilepsy in Sucevita, Romania. The main themes: Investigations in Epilepsy; Treatment in epilepsy – 10-13 July 2019 http://ilae-romania.ro/scoala_vara_2019-2/
- The XXVIIth Annual SRIE Conference –14-16 Nov 2019 Bucharest
- Renew and reprint – Informative booklet for patients with epilepsy
- Extend cooperation with neighbor countries from Eastern and Center Europe for exchange and development

Officer Election Date: Nov 2019

SAUDI ARABIA: Saudi Chapter of Epilepsy

Report By: Raidah Al-Baradie

Publications:

Status Epilepticus guidelines in Saudi Arabia

Summary of Activities:

- Pediatric Neurology Symposium held at Abha, Aseer Central Hospital on 14 January, 2017
- Participated in CEMA congress held on 16-18 February 2017 @ Luxor in Egypt
- Saudi Pediatric Neurology Symposium collaborated with SCE was held on 27-28 February 2017 @ Prince Sultan Military Medical City, Riyadh
- One day course was conducted about the Diagnosis &

Management of Epilepsy in Adults and Pediatric @Hail & Abha on 23 March 2017

- Epilepsy shut down has been conducted @ Novatel Hotel, Dammam, connected with 13 different centers in the Middle East under the umbrella of SCE on 12May, 2017
- Epilepsy Awareness Day held in various regions under the umbrella of SCE
 - o Jeddah- held on 30 March 2017 @ King Abdulaziz University Hospital
 - o Jubail- held on 3April
 - o Makkah- held on 12 April 2017 as workshop and 13 April, 2017 awareness day. 2nd awareness Day held on 30 April 2017
 - o Dammam- held on 6 April 2017 @ Al Othaim Mall
 - o Al Hassa - held on 6 April 2017 @Al Othaim Mall
 - o Riyadh - held on 6 April 2017. Awareness campaign done in 11 schools as well. 2nd Awareness day also held
 - o Al Qaseem-held on 13 April 2017 @Al Othaim Mall
 - o Najran- held on 28 April 2017 @ King Fahd Central hospital. Also done workshop on 12April, 2017
 - o Abha 14 January 2017
 - o Society is affiliated under Saudi Commission
- Epilepsy shut down has been conducted @ Kempenski Hotel, Al Khobar connected with 13 different centers in the Middle East under the umbrella of SCE on 15 December 2017
- 7th SES & 4th GCC conference was held on 16-18 February 2018 @ Al Faisal university auditorium, Riyadh.
- SPNS Symposium collaborated with SCE was held on 6&7 March 2018 @ Jeddah
- Activity done about ABC in Epilepsy conducted @ King Abdullah main Auditorium, Jeddah on 29 & 30 March 2018
- Epilepsy Awareness Day held in various regions under the umbrella of SCE
 - o Riyadh- held on 25 March 2018
 - o Makkah- held on 26 March 2018
 - o Qatif - 10 May 2018

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o Dammam- 19 July @ Al Othaim Mall

- Epilepsy shut down has been conducted @ Kempenski Hotel, Al Khobar connected with 13 different centers in the Middle East under the umbrella of SCE on 15 May 2018
- Epilepsy Course was conducted in Riyadh on 13 October 2018

Challenges:

- Finalize the epilepsy and driving regulations
- Finalize VNS guidelines in Saudi Arabia
- Increase the awareness in remote regions
- Establish tele-medicine in epilepsy
- Maintain Gulf League Against Epilepsy collaboration

Future Plans:

Organize the Saudi Chapter conference in epilepsy in Oman (First time to have SCE in gulf region)

Maintain gulf collaboration in various aspects (meetings, research, managing patients etc.)

Establish tele-medicine in epilepsy in remote regions in Saudi Arabia and then gulf regions.

Conduct election in 2019

Officer Election Date: March 2019

SERBIA: Serbian League Against Epilepsy

Report By: Assoc. Prof. Aleksandar Ristic, Chapter President and Assoc. Prof. Stevo Lukic, Chapter Vice President

Publications:

Series of proceedings: "Epilepsy and comorbidity?" (19th Epilepsy School, 2017), "Adverse effects of antiepileptic therapy" (20th Epilepsy School, 2018).

Summary of Activities:

11th Congress of Serbian Neurologists with international participation (Belgrade, November 24-26, 2017) included

teaching courses and a number of sessions on epilepsies. Educational cycle of Epilepsy School courses: - 19th Epilepsy School, September 2017 - 20th Epilepsy School, October 2018 - 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.

Challenges:

No activities of local IBE were recognized for years, and no activities in conjunction with local IBE. Chapter does not find that local IBE still exists.

Future Plans:

- 21st Epilepsy School, Zlatibor, Serbia, October, 2019
- ILAE Migration Course Sabac, Serbia, September 2019
- 12th Serbian Neurology Congress, Belgrade, November 2019.
- Development and application of Seizure diary application for mobile devices.

Officer Election Date: 18-Dec-2018

SLOVAKIA: Slovak League against Epilepsy

Report By: Vladimir Donath

Publications:

Rivera GAR: Epileptic Enecephalopathies

Donath V.: Valproate

Donath V. New Classification of Epilepsies and Epileptic seizures

Klobučníková K. et al. The Comorbidity of Focal Epilepsy and Narcolepsy Type 1 - Two Case Repots. Neurocrinology Letters, 39, No. 2, 2018, 101-104.

Summary of Activities:

Cooperation in organizing

- Common Czech and Slovak Congress of Neurology

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- Common Czech and Slovak Congress of Pediatric Neurology
- XXX. Czech and Slovak Congress of Epileptology
- CONY Congress Lisbon 2018

Challenges:

- Epilepto-surgical program
- Engage young neurologists into epileptology
- Work to improve epilepsy care in cooperation with Ministry of Health

Future Plans:

- Enhance educational activity in epileptology
- Organization of XXIII. Common Slovak and Czech Epilepsy Congress
- Educational course on EEG and Epileptology

Officer Election Date: 2020

SLOVENIA: Slovenian League Against Epilepsy

Report By: President, Natalija Krajnc, MD, PhD, Child Neurology Consultant

Publications:

See Summary of activities

Summary of Activities:

Lectures about epilepsy for laic community and patients:

- We have continued established activities with regular lectures for relatives of persons with epilepsy, separately for parents/relatives of children with newly diagnosed epilepsy, for teachers in schools / kindergartens: 10 lectures in 2018.
- Public events to promote knowledge about epilepsy: performed in two cities (Trbovlje and Murska Sobota)
- Symposia for health professionals:
 - Epilepsy and neuroradiology, in cooperation with Slovenian Medical Association (SMA) and invited guest Walter van Emde Boas, May 2018,
 - Epilepsy in Children and Adolescents, with workshop, in cooperation with Child Neurology Society of SMA, October 2018.

Support with accompanying persons referred for presurgical evaluation/epilepsy surgery abroad:

- 23 referrals assisted (some patients needed 2-3- times)

Supporting self-help groups of patients:

- Groups active in 5 cities (Ljubljana, Koper, Nova Gorica, Kranj and Ptuj).

Contact phone EPITEL:

- Available once a week on regular schedule.

Printed materials:

- Booklet »Epilepsy Diary«
- Journal of our Chapter named Žarišče: one issue per year
- Posters related to International Epilepsy Day.

Web site: announcements about activities and links.

Events related to International Epilepsy Day:

- Press conference for media
- Event for public in city Nova Gorica with cultural connotation
- Poster promotion.

Active participation in IBE Europe with our representative Ljubica Vrba.

Financial support for these activities is provided by donations, projects of Humanitary Foundation and Ministry of Health.

Challenges:

See Summary of activities

Future Plans:

Continued activities at least at the level of previous activities. Efforts for funding with projects of Ministry of health.

Officer Election Date: March 23, 2019

SOUTH AFRICA: South African Chapter of ILAE

Report By: Dr R Govender

Summary of Activities:

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Paediatric Epilepsy Activities: PET

The past year was a fruitful one in terms of epilepsy related meetings/activities in South Africa. A number of Paediatric Epilepsy Training 1 (PET 1) courses were held throughout the country. The PET course is an initiative of the British Paediatric Neurology Association (BPNA). A South African faculty was trained to teach the course in Feb 2016. This course has been developed to improve practice within childhood epilepsies. It is suitable for all health professionals providing primary or secondary level care for children with epilepsy.

The meetings held this year were as follows:

1. Paediatric Epilepsy Training Course 1- 12/5/2018- East London. Dr Isabel Michaelis was the faculty chair and there were 22 attendees.
2. PET Course 25/8/2018- Durban. Dr Lawrence Mubaiwa was the faculty chair and there were 46 attendees.
3. SAPA meeting with PANDA track – 30/8/2018- 1/9/2018- Cape Town. This meeting covered a range of paediatric neurology topics including epilepsy
4. PET Course 20/10/2018- Cape Town. Professor Regan Solomons was the faculty chair and there were 46 attendees. This PET course marked the 3-year audit by BPNA of the standard of the South African teaching courses. Professor Helen Cross attended this course to conduct the audit.
5. PANDA Weekend 21/10/2018- Cape Town. The annual PANDA weekend took place at the Sports Science Institute and the focus this year was epilepsy. The program covered a range of pertinent topics in paediatric epilepsy including genetics of epilepsy, epilepsy surgery and co-morbidities in epilepsy. Professor Helen Cross together with local faculty presented the talks. There was also an interesting case presentation session where interesting and challenging patients were presented. There were 66 attendees at this meeting.

In addition, other PET 1 courses were held in other parts of Africa and were supported by a South African faculty. These included:

1. April 2018 – Kenya – this included an extended African faculty (92 delegates, and an additional 25 African faculty were trained). The South African faculty that supported this meeting were Professor Jo Wilmshurst and Professor Gail Scher.
2. May 2018- Ghana (Kumasi) – 94 attendees Professor Jo Wilmshurst supported the first PET there.
3. September 2018-Tanzania (Dar) – 61 attendees Dr. Gill Riordan supported the first PET there.
4. Nov 2018 – Kenya – Professor Gail Scher supported the PET course there.

Adult Epilepsy Events South Africa 2018

1. The Neurology Association of South Africa held their annual congress in March of 2018, at the Elangeni Hotel, Durban. Prof AI Bhigjee hosted the meeting. The congress saw a dedicated focus on developments in the field of epilepsy. An EEG workshop focusing on the practical analysis of EEGs was held. The Groote Schuur faculty made up of Dr L Tucker, Dr E Lee Pan and Prof R Eastman (emeritus) chaired the session. Invited international speakers included Prof S Irani of the Nuffield Department of Neurosciences, Oxford. He presented on his extensive work in the identification and description of auto-immune epilepsies. Prof Matthew Walker of the UCL institute of Neurology, Queen Square, also made up the faculty. Topics included the Ketogenic diet, advances in AMPA receptors and Gene Therapy in the management of Focal Epilepsy.
2. World Congress on Epilepsy and Brain Disorders was held at the V&A waterfront, Cape Town on 22-23 November 2018. The theme of the congress was the “Elimination of Epilepsy”. The faculty included both international and local speakers. The invited African faculty included Dr T Farombi, Neurologist – Nigeria; Dr JJ Labuschagne, Neurosurgeon – South Africa and Dr CN Lownie, Child Psychiatrist – South Africa. The international faculty included speakers from India; Argentina and Canada. The conference which hosted more than 100 participants, encouraged collaborations amongst psychiatrists, neuro-surgeons, neurologists, and researchers in the field of epilepsy.
3. In addition, the Neurological Association of South Africa (NASA), in collaboration with the University of Cape Town has developed an online distance learning program that is designed to assist the training of neurology registrars in the principles and practice of clinical electroencephalography. The program is run as a part-time course over 6 months, covering 9 modules, lasting 3 weeks each. Online forums with discussion

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amongst students and tutors are also available. Conveners of the program include Dr L Tucker, Prof R Eastman (emeritus) and Dr E Lee Pan. This year saw the successful continuation of the program following its launch more than a year ago.

Challenges:

Gaining government advocacy

Future Plans:

Panda epilepsy weekend 2019

Officer Election Date: 17 August 2018

SOUTH KOREA: Korean Epilepsy Society

Report By: Dong Wook Kim MD, Secretary Director

Summary of Activities:

June 2018: Annual meeting of Korean Epilepsy Society

December 2018: Publication of the first we-zine for Korean Epilepsy Society

Members of Korean Epilepsy Society are working for the law about "Care and Support for Epilepsy Patients" We hope the law is implemented in 2019 and epilepsy patients will benefit from the law.

Challenges:

Nothing to report

Future Plans:

- Feb 2019: Two-day epilepsy mini-fellowship for resident doctors and young neurologists and neuro-pediatrics
- Feb 2019: Nationwide celebration and education program for international epilepsy day
- March 2019: Cannabinoids for epilepsy workshop
- June 2019: Annual meeting of Korean Epilepsy Society

Officer Election Date: September 2018, Dr Jae-Moon Kim was elected for new president of Korean Epilepsy Society

SWEDEN: Swedish Epilepsy Society

Report By: Ulla Lindbom, president

Publications:

Preliminary presentation of National Guidelines for Epilepsy, May 2018

Summary of Activities:

- Since the constitution 1986, the Swedish Epilepsy Society holds annual meetings every November. In 2017 the meeting took place in Linköping and in 2018, in Lund.
- Chapter meetings: 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. Spread and further development of the Epilepsy register is another important field.
- A workshop was held in February 2017 with the title "Childhood epilepsies, effects on language, cognition and behaviour."
- In May 2017 a workshop was held on the theme "Epilepsy healthcare at a distance."
- The Annual Meeting November 2017 focused on "Cognition and behavior problems in patients with epilepsy."
- In January 2018, a workshop was arranged titled: "Workshop on using MEG in pre-surgical evaluation of epilepsy patients."
- The Annual Meeting November 2018 focused on "National Guidelines for Epilepsy."

Educational Activities:

- A national epilepsy register for children was completed and implementation started during 2016. The epilepsy registry for adults started in 2014 and the implementation for expanded use among colleagues over the country is ongoing, but the progress is slow.
- We offer an annual educational course for neurology residency training as well as update 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.
- In 2016 the process of conducting National Guidelines for

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epilepsy started at the request of the Swedish Government and the work has been completed during 2017 and 2018.

The guidelines are planned to be published February 2019 and applies to both adults and children.

- ✦ The Society established clinical advices 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.
- ✦ During 2018 the work with updating the Guidelines for drug treatment of epilepsy from 2011, have been in progress and will be published during spring 2019.
- ✦ Activities in Conjunction with Local IBE Affiliates:
 - o Representatives from the local IBE have been active in taking part in the development of the National Guidelines for epilepsy as well as the in the continuous work to spread the use of the Epilepsy register.
 - o Media contacts and press releases.
 - o Local joint activities in different cities on the International Epilepsy day.

Challenges:

Implementation of the National Guidelines for equal and adequate care of patients with epilepsy is the priority for the Swedish Chapter in the next few years. To be able to follow the compliance with the guidelines we need indicators that can give continuous information. The epilepsy registry is an excellent tool for this purpose but the coverage over the country is far from adequate and we need to develop IT technology to facilitate the use of the epilepsy registry.

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 to introduce the National Guidelines for equal and adequate care of patients with epilepsy is our priority. Spread and further development of the Epilepsy register is another important field. During 2019 the updated guidelines for AEDs will be published and the Annual Meeting 2019 will have these guidelines in focus.

Officer Election Date: November 15, 2018

SWITZERLAND: Swiss League Against Epilepsy

Report by: Dr. Julia Franke

Regular Publications

Journal "Epileptologie" (Epileptology), publication four times a year, 50 - 70 pages each, with information about new developments in epilepsy research and treatment (for professionals, 1100 copies). Articles in English, German, or French with summaries in all three languages.

- ✦ Topics 2017: Neurostimulation / Contemporary Issues in Pharmacotherapy of Epilepsy / Mortality in Epilepsy / Epilepsy Surgery in Children
- ✦ Topics 2018: Genetics / Specialised offers for people with epilepsies in Switzerland / Dissociative seizures / Pharmacoresistant Epilepsies
- ✦ Future plans, see below.

Print newsletter "*Epilepsie-News*", publication three times a year, 4 pages each, with information about our activities and about epilepsy (for donors and members, about 12.500 copies in German, about 3.000 copies in French and 2000 in Italian).

- ✦ Future plans: "*Epilepsie-News*" will be discontinued for financial reasons.

Annual booklet on events in German and French (will be discontinued as well)

Annual report (German, French)

Continuing presence on Facebook

Monthly e-newsletter (about 8,000 German-speaking and 2,000 French-speaking recipients)

E-Newsletter for doctors (about 5-6 times per year)

Summary of Activities

Annual meetings

2017

- ✦ 10th Joint Meeting of the German, Austrian and Swiss

Chapter Reports *(continued)*

Chapters of the International League Against Epilepsy (ILAE) in Vienna, Austria. May 3 to 6, 2017.

2018

- ♦ Annual Meeting of the Swiss Society of Clinical Neurophysiology and the Swiss League against Epilepsy, Aarau, Switzerland, May 30 and 31, 2018.
- Participation in different scientific events.

Summary of other activities in 2017 and 2018

- ♦ Relaunch of website www.epi.ch (German, French, Italian, English): New responsive layout, additional content, including more information in English
- ♦ Annual Research Recognition Award (CHF 25'000) for the most promising research study in Switzerland in the field of epileptology
- ♦ Biannual Hauptmann Award in 2017 (Euro 10'000) in cooperation with the German and Austrian chapter
- ♦ New information leaflet "Epilepsy and Sleep" (German, French, Italian)
- ♦ Information in migrant languages: four information leaflets published in Albanian and Portuguese (also on www.epi.ch)
- ♦ Three professional events per year with about three lectures each, for professionals in different cities
- ♦ About 5-6 events for non-professionals in cooperation with Epi-Suisse (IBE chapter), in different cities and language regions
- ♦ Special events for "epilepsy day": theatre performance (2017), lecture about Dostoevsky's epilepsy (2018)
- ♦ Tissot Medal (honorary prize for special services to Swiss epileptology) to Prof. Dr. Paul-André Despland, former president of the Swiss League Against Epilepsy
- ♦ Campaign "Epilepsy in the elderly": training events for (geriatric) nurses and PR in German and French
- ♦ New ILAE classification translated into German (with German and Austrian chapters)
- ♦ Media activities
- ♦ Answers to medical questions, about 150 questions a year

Challenges

Finances: The league is mainly financed by donations – membership fees, sponsoring, legacies and foundation are

not sufficient to finance the operation and all projects. Until the end of 2016, an old contract guaranteed regular net donation receipts. After its expiration in 2017, the league hired a new fundraising partner, but success failed to materialize. With yet another fundraising specialist, net receipts and the number of donators are on the rise, but it will take a few years until the budget is balanced again – hence the austerity measures.

Future Plans

- ♦ 2019: 11th Joint Meeting of the German, Austrian and Swiss Chapters of the ILAE in Basel, Switzerland. 8 to 11 May, 2019. <https://www.epilepsie-tagung.de>
- ♦ 2020: 14th European Congress on Epileptology (ECE) takes place in Geneva, Switzerland, 4 to 8 July 2020.
- ♦ A new, trinational journal with the German and Austrian chapters, in German and English, is to replace our journal "Epileptologie"
- ♦ Only one special edition of "Epileptologie" planned for 2019: Population survey concerning attitudes towards epilepsy in Switzerland, compared to Germany and Austria (survey carried out in 2018)
- ♦ 2019: Short film "First aid epileptic seizures", mainly for training events and social media, in cooperation with Samariterbund (Swiss Samaritan League)
- ♦ Revision of guidelines concerning driving with epilepsy
- ♦ New or revised information leaflets: Maternity with epilepsy; driving with epilepsy; children with epilepsy
- ♦ More information in migrant languages (English; Serbian/Croatian)
- ♦ "E-book" (PDF containing all leaflets for tablet computers)

Officer Elections: May 2018

New treasurer, Mr. Marco Beng; new board members, Ms. Noëlle Mercier and Mr. Johannes Sarnthein.
Re-elected: President, Mr. Stephan Rüegg; new Vice-President, Mr. Andrea Rossetti; Ms. Pamela Agazzi, Mr. Alexandre Datta, Mr. Thomas Grunwald, Ms. Anna Maria Hew-Winzeler, Mr. Klaus Meyer, Mr. Kaspar Schindler, Ms. Margitta Seeck, Mr. Urs Sennhauser.

Retired, past-president, Mr. Günter Krämer, Ms. Malin Maeder, Mr. Markus Schmutz, Mr. Elmar Zwahlen.

Chapter Reports *(continued)*

Next election: Spring 2020.

TAIWAN: Taiwan Epilepsy Society

Report By: Chien Chen, Secretary General

Publications:

1. Taiwan guidelines for management of Epilepsy, 3rd version
2. Taiwan EEG guidelines, 2nd version
3. Taiwan guidelines for management of pediatric Epilepsy, 1st version
4. Taiwan guidelines for management of post-stroke epilepsy

Summary of Activities:

1. Annual meeting of Taiwan Epilepsy Society was held on April 21-22, 2018, at Sheraton Grande Taipei Hotel. We defined the meeting as “targeted management of epilepsy in different group”. There was a pre-congress meeting “talking with masters” in the afternoon of April 21. We have 6 young adult neurologists and pediatric neurologists in the session to present interesting cases for interactive discussion, with our honorable guest
2. April 27-28- ASEPA EEG master class (April 27) and ASEPA EEG examinations (April 28, writing and oral test)
3. “Introduction of Epilepsy” has been conducted three times in 2018. 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.
4. By request of Kantipur Dental College Teaching Hospital & Research Centre Dhapasi, our society held a epilepsy education course on 06-07 Oct 2018, at Kathmandu, Nepal. Under the organization of professor Ching-Shiang Chi, Taiwan outstanding epileptologists professor Jing-Jane Tsai, professor Shang-Yeong Kwan, Dr. Chu-Chin Chen, pediatric neurosurgeon Dr. Hsin-Hung Chen and the secretary general, Dr. Chien Chen; hosted a comprehensive education program about clinical epileptology. We have more than 30 medical doctors of Nepal in the program and all participants experienced

fruitful meeting and interactive workshop.

5. “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. (Nov 11, 2018).
6. “Introduction and Managing Patients with Epilepsy” are conducted three times in 2018, in order to provide comprehensive epilepsy education to nursing professionals.

Challenges:

- ✦ Limited financial support
- ✦ Social stigma

Future Plans:

1. More frequent education course for general population to lessen the influence of social stigma
2. More international education courses

Officer Election Date: April 28, 2019

THAILAND: Thailand Epilepsy Society (EST)

Report By: Kamornwan Katanyuwong M.D.

Publications:

- ✦ Thai Official Educational Bulletin - Epilepsy Digest: 3 issues in 2017 and 2 issues in 2018. This bulletin can be accessed via EST’s official website. www.thaiepilepsysociety.com
- ✦ The guideline for HLAB*-1502 screening in Thai epileptic patient, published in 2018.

Summary of Activities:

In July 2017, the 10th Executive Board commenced administrative roles for a two-year term.

1. Annual Meetings

- ✦ 2017: 21st Annual Scientific Meeting Theme: Epilepsy and its Pathologies, July 20 -21. International guest speakers were Prof. Emilio Perucca (Italy) and Prof. Helen Cross (UK).

Chapter Reports *(continued)*

- 2018: Pre-congress Conference including: EEG monitoring; SEEG; fundamental neuroimaging; voxel-based morphometry; EEG/fMRI, July 18.
- 2018: 22nd Annual Scientific Meeting Theme: Implementing Good Practice in Epilepsy Care, July 19 -20. International guest speakers were Prof. Akio Ikeda (Japan) and Prof. Lakshmi Nagarajan (Australia).

2. Educational Activities

- A two-day epilepsy educational course, free-of-charge, was conducted for pediatric neurology fellows and senior neurology residents, August 8, 2017 and September 9, 2018.
- The Inter-hospital Epilepsy Surgery Conference including: case discussion; topic review and EEG/MRI quiz, held 4 times per year.
- Advanced EEG Workshop for Practitioners, November 24, 2017.
- EST's committee members participated as speakers in different scientific meetings e.g. Annual Meeting of the Neurology Association of Thailand (NAT) and the Regional Meetings NAT, 3-4 times per year.

3. Bursary Support

- Grants to pediatric neurology fellows, neurology residents and young neurologists for the International Congress.

4. Activities in relation to the Epilepsy Association of Thailand (EAT)

- Epilepsy camps were held for epileptic patients in the Chiang Mai regional area on March 26, 2017 and March 17, 2018.
- Bangkok also held an epilepsy camp for epileptic patients on November 25, 2018.
- Campaigns were organized for public education and awareness of epilepsy, for International Epilepsy Day and Purple Day, 2017 and 2018. University hospitals and major government hospitals around the country participated.
- Social media i.e. Facebook, YouTube, broadcast communication and news were utilized to increase awareness of epilepsy.

- Fundraising included a Running Day for epileptic patients. This was commenced in 2017.
- EAT members were assisted financially to attend the International Epilepsy Meeting.

Challenges:

- The Thai Government is currently developing a policy which allows for cannabidiol products to be used legally for specific medical conditions. The EST Committee has provided information to assist this process and has delivered recommendations around patient suitability.
- The EST has been involved in the process of developing guidelines for new laws for epileptic drivers.

Future Plans:

- The EST is honored to be the local host of the 33rd International Epilepsy Congress in Bangkok Thailand, June 22-26, 2019.
- To encourage the Thai government to consider integrating epilepsy into the Government-support Service Plan.

Officer Election Date: June 2019

TURKEY: Turkish Epilepsy Society

Report By: Kezban Aslan

Publications:

Journal of Turkish Chapter of International League Against Epilepsy (in Turkish)

Summary of Activities:

Meetings:

- Epilepsy symposium, 5-7 May, 2017
- National Epilepsy Congress of Turkish chapter of ILAE , 5-8 May, 2018

Summary of Activities in 2017-2018:

- Epilepsy meeting, monthly, 2017-2018
- Semiology/ Clinical finding of Epilepsy, Workshop, 1 April 2017
- Status Epilepticus, Workshop, 29 September 2018
- EEG course (Pattern), 23 September, 7 October 2017, 21-22 September 2018

Chapter Reports *(continued)*

- † Epivizyon, advanced epilepsy course, 3 November 2017
- † Semiology/ Clinical finding of Epilepsy, Workshop, 1 April 2018
- † Sivas Epilepsy Symposium II, 13 May 2017
- † Episkop, case discussions, 18 March 2017
- † Episkop, case discussions, 10 March 2018
- † Epilepsy, Eskişehir Student Symposium, 19 March 2018

Summary of Activities in Relation to Global Campaign in 2017 and 2018

- † Painting contest with epilepsy among children and adolescents
- † Photograph contest in epilepsy patients.

Educational Activities:

- † EEG course, in four different cities.
- † Epilepsy course, National Neurology Congress, 2017 and 2018
- † Bursaries to young to neurologists for local and international congress
- † Activities in conjunction with local IBE Affiliate
- † Financial support
- † Medical and social consultancy

Challenges:

- † We would like to improve knowledge about the epilepsy of the assistant and student.

Future Plans:

- † Epilepsy symposium, 3-5 May, 2019
- † National Epilepsy Congress of Turkish chapter of ILAE, 2020
- † Educational activities, EEG, epilepsy course

Officer Election Date: May 2020

UGANDA: Uganda League Against Epilepsy

Report By: Dr Angelina Kakooza

Summary of Activities:

View photos of these activities in the Ugandan Chapter Spotlight

Early Childhood Development: Dissemination Workshop on Epilepsy

May 10, 2017 at the Grand Global Hotel, Kampala, Uganda
This workshop was held under the leadership of Dr. Angelina Kakooza. M – President to disseminate the results of a large multisite study entitled “Studies of Epidemiology of Epilepsy in Demographic Surveillance Systems (SEEDS) study funded by a Wellcome Trust Senior Fellowship in Clinical Tropical Medicine to Prof. Charles RJ Newton. This study was conducted across five health demographic surveillance systems (HDSS) in Africa (www.indepth-network.org) from December 2007 to April 2011. The overall aim of these studies was to determine the prevalence, risk factors and outcome of epilepsy in 5 sites across sub-Saharan Africa. The Uganda site was based at Iganga/ Mayuge HDSS in Uganda, with Dr Kakooza M.A as the site Principal Investigator. The purpose of the half-day dissemination workshop was to share the study findings with the key stakeholders, raise awareness regarding epilepsy in Uganda, inform and educate the community regarding its screening and assessment, discuss the study recommendations, engage and obtain feedback from various stakeholders in the field of epilepsy and other childhood disabilities, and stimulate further research in this area.

The key findings from the SEEDS study were that epilepsy is a common problem in this rural area of Uganda, with an estimated overall prevalence of 10.3 per 1000 persons. The prevalence is highest amongst the younger age group and declines with age with focal onset seizures, being the most common seizure type. As a result of the community’s perceptions of the supernatural causes of epilepsy, a high level of stigmatization was observed in these individuals, which forces them into isolation and contributes to their limited social and economic opportunities. The larger percentage of persons with epilepsy are unaware of their diagnosis and are not receiving treatment, with many preferring to use traditional medicines rather than anti-epileptic drugs (AEDs). Regarding the children, a history of complications in the antenatal period and adverse perinatal events were identified as important risk factors for epilepsy, whereas a family history of seizures was the factor most strongly associated in the adults.

Chapter Reports *(continued)*

Symposium on Epilepsy and Childhood Disability

May 11-12, 2017 at the Grand Global Hotel, Kampala, Uganda

The presentations and discussions during the symposium paved the way for opportunities to advocate for the needs of children with disabilities and the professionals and parent support groups necessary to support their care in all parts of the Ugandan region. The workshop and symposium were well-attended, and participants were also able to learn about early childhood development and disability from various national and regional perspectives and share professional experiences in the communities of the East African region. Meeting attendees were from Uganda, Kenya, Ethiopia, United States, Sweden and the United Kingdom. The meeting participants included the Assistant Commissioner in charge of Early Childhood Development from the Ministry of Education and Sports, Mr. Ibrahim Bigabwa, the UNICEF Early Childhood Development specialist, Ms. Divya Lata, and the Resident District Commissioners of Iganga and Mayuge, Captain Ben Turyahumura and Mr. Ogasa Barasa respectively, the District Director of Health Services representative (District Health Inspector) for Mayuge district, Mr. Gidudu Richard and the Program manager for the Disability section in the Ministry of Health, Mr. Nsimenta Dennis.

Paediatric Epilepsy Training (PET) Courses

Part of the ILAE- Africa strategic plan is to conduct training in epilepsy and strengthen the education activities in the region. A series of Paediatric Epilepsy Training (PET) courses were conducted on the 7th and 8th of August 2018 at the Faculty of Food Science and Technology, Makerere University in collaboration with the British Pediatric Neurology Association (BPNA) and the Uganda Pediatric Association (UPA).

The training was conducted by 8 faculty members who are all pediatricians namely: Dr. Richard Idro, Dr. Angelina Kakooza, Dr. Shema Christine, Dr. Vivian Ssonko, Dr. Chebet Martin, Dr. Robert Sebunya, Dr. Kayina Vicent and Dr. Kalubi Peter

Dr. Mike Pike from the BPNA- United Kingdom came to Uganda to oversee the training. A total of 92 participants were trained with 45 trained on the 7th August 2018 and 47 trained on the 8th August 2018. The participants

included pediatricians, psychiatrists, residents in pediatrics, medical officers, clinical officers, psychiatry clinical officers, psychiatry nurses. The teaching was a mixture of both lectures for the whole group and workshops in which participants split up into small groups.

Symposium on Epilepsy in Children

September 20-21, Rock Classic Hotel, Tororo Town, Uganda

Epilepsy Society Uganda (EPISOU) in conjunction with Uganda Medical Association (U.M.A.) – ELGON REGION BRANCH and the Uganda Pediatric Association (UPA), conducted a Symposium on Epilepsy in children in Tororo Town, Uganda.

Symposium Objectives

The Objectives of the Symposium and related activities were threefold.

1. To raise awareness in the public with a view to create an atmosphere for prevention, early detection/diagnosis, effective treatment, and reduction of stigmatization and discrimination of people with epilepsy (PWE).
2. To update and improve the knowledge and ability among health professionals, and motivate and equip them, to give better preventive interventions, and care, for people with epilepsy.
3. To build and/or improve strategies, for better prevention of, and care for people with and/or affected by, epilepsy in the sub-region.

Major Symposium Activities

- Local FM Radio talk Shows in English and the local languages of Ateso, Adhola, and when necessary Luganda.
- Scientific Presentations on Day 1 of the two day targeting 100 health professionals working in various hospitals and health centers (including private health units) in the region (doctors, nurses, and clinical officers).
- Day 2 of the symposium targeted about 80 people/ patients with epilepsy, their care givers, community health workers (CHWs), along with key health professionals, and local leaders, with the three aims providing basic facts on epilepsy, sharing experiences and challenges, and developing strategies for the

Chapter Reports *(continued)*

prevention, early diagnosis, and better care of epilepsy. Interacting with and sharing meals with people with epilepsy and their care givers inspired them and lessened stigma.

Target Groups

1. The General Community or Public.
2. The Affected Community including PWE, Parents, and Care-givers.
3. The Caring Community including Health Care Professionals and Supporting Partners.

Achievements

- All the three symposium objectives were achieved.
- Attendance was over 80% on Day 1, and over 75% on Day 2, of the expected number. The total registered attendance on Day 1 of the symposium was 83 out of an expected 100, and 61 out of an expected 80 participations for Day 2. These included participants from the regional districts of Tororo, Busia, Butaleja, Pallisa, Mbale, Kwen, and Kapchorwa.
- On Day 2, during the session Joining Hands Against Epilepsy, the empowered participants resolved to form a regional forum or association whose membership will include not only the people with epilepsy but also their care givers, health professionals, teachers and/or educators, administrators, and almost any other persons affected by epilepsy – to address the needs and challenges posed by epilepsy in the region and beyond. This promises to be a powerful morally therapeutic and inspiring fellowship, as well as a lobby and/or advocacy platform for People With Epilepsy.

Challenges:

- Low community awareness of epilepsy in general.
- High levels of stigma for people with Epilepsy (PWE) limiting their acceptability in society.
- Large epilepsy treatment gap estimated at over 80%.
- Absence of standardized treatment guidelines for epilepsy and weak referral systems.
- Minimal support from stakeholders regarding the proper management of people with epilepsy.
- The loss of our Secretary General, Mr. Augustine Mugarura who passed on the 14th October 2018, may his soul rest in eternal peace

Future Plans:

- Set up some regional satellite sites country wide for EPISOU members to carry out epilepsy advocacy and public outreach activities in their respective localities.
- Identify Ugandan Epilepsy Champions to share their successful real life stories and advocate for appropriate Epilepsy care in terms of the need for prompt diagnosis, seeking the right treatment, adherence to medications and thus contribute to the epilepsy stigma reduction.

Officer Election Date: April 2019

UKRAINE: Ukrainian League Against Epilepsy

Report By: Volodymyr Kharytonov

Publications:

Translation into Ukrainian of “Instruction manual for the ILAE 2017 operational classification of seizure types,” “ILAE classification of the epilepsies: Position paper of the ILAE Commission for Classification and Terminology,” “A practical clinical definition of epilepsy,” and “Operational classification of seizure types by the International League Against Epilepsy: Position Paper of the ILAE Commission for Classification and Terminology.”

Summary of Activities:

- XXII Scientific and Practical ULAE Conference with International Participation “Epilepsy – Window for Brain Cognition: What’s new”, MAY 17-19, 2018
- DNIPRO, 4TH EAST EUROPEAN COURSE OF EPILEPSY: Age aspects of Epilepsy 13-15 JUNE, 2018 with PRESIDENTIAL SYMPOSIUM (32nd ILAE CONGRESS 2017)
- Video-recording with translation Participants: 250
- CHERNIHIV Participants 156 http://ulae.org.ua/attachments/article/18/IV%20EECE%20ILAE-CEA%20Chernihiv%20Ukraine_JUN13-15%202018_report.pdf

Challenges:

Problems with Ministry of Health communication, lack of statistic data, problems with medication reimbursement

Chapter Reports *(continued)*

Future Plans:

- Educational course EEG & Epilepsy, March 1-2, 2019 KYIV
- XXIII Scientific-practical conference of ULAE with international participation MAY 16-18, 2019 ODESA II Regional Ukrainian Congress CONTROVERSIES IN NEUROLOGY NOVEMBER 21-22, 2019 KYIV
- <http://ulae.org.ua/index.php/en/congresses/future-events>

Officer Election Date: Previous: 27.05.2017, Next May 2021

UNITED STATES: American Epilepsy Society

Report By: Eileen M. Murray

Publications:

Epilepsy Currents

Summary of Activities:

2) Board and Governance

Realigned committees under the Council on Education for more effective oversight and execution of programs. Created an Early Career Grant Committee. Gathered data on gender diversity in AES leadership roles and awards to inform work of future task force. The Basic Science Task Force, appointed by Dr. Mizrahi, identified important actions we are now implementing to re-engage and better serve our basic science community. AES became a member of the AMA Specialty and Service Society, as part of the Neurology Section Council. The Board approved Key Performance Indicators to better track progress against strategic goals.

3) *Epilepsy Currents*

Impact factor rose to 9.33. We are completing a transition to new publisher, Sage Publishing, effective with publication of the January/February 2019 issue. It is expected that with this new partnership we will expand the reach and impact of the journal.

4) Education

First 21 modules of Fellowship Curriculum launched. Performance Improvement CE Module on Improving Outcomes for Transitions from Pediatric to Adult Epilepsy Care produced and approved by ABPN for MOC credit.

Self-assessment Volume 5 launched with ABPN approval for MOC credit, Volume 6 in development. Ask-the-Expert webinar on Infantile Spasms, Transition from Pediatric to Adult Care both produced and also available online. Two Depression and Anxiety Handouts were created, for pediatric and adult. AES led the 4th biennial PAME conference – AES provided education, fundraising and meeting management. Online education module on diagnosis and treatment of LGS – funded by grant from Lundbeck and produced in partnership with the France Foundation and LGS Foundation, available via Medscape. New initiative launched to deepen engagement of APPs and better meet their resource needs launching at this annual meeting.

5) 2018 Annual Meeting

Number of abstracts – 1,350 accepted. Investigator Workshops – submissions tripled to 37, accepted 17. Held a CAAE joint international forum. Fellows program continues to evolve in response to fellow feedback – expanded professional development sessions, more opportunities for peer-to-peer networking, more focused mentor connections. We expanded the career pathways panel and career skills training sessions, open to all attendees.

6) Clinical Activities

- Publication of Practice Guideline Update on the Efficacy and Tolerability of New Antiepileptic Drugs: Treatment of new-onset epilepsy and Efficacy and Tolerability of New Antiepileptic Drugs: Treatment-resistant epilepsy Guidelines – joint effort with AAN. AES commented on the AAN on Practice Advisory on timing of antiepileptic medication withdrawal in seizure-free patients.
- Published AED Reference Table in print and online. AES submitted a comment letter to the FDA on streamlining the development of new, potentially less expensive, drugs and devices to improve the range of treatment options available to patients, particularly for treatment of rare or orphan indications.
- There have been two revisions to AES position statement on Cannabis as a Possible Treatment for Epileptic Seizures.
- Position Statement on Immediate Access to Accepted

Chapter Reports *(continued)*

Treatments for Infantile Spasms was approved and endorsed by 10 epilepsy organizations.

- ♦ AES provided a letter of support for ICD-10 Code for Dravet Syndrome. We submitted a comment letter to Tricare regarding concerns about change in policy on access to treatments for infantile spasms – requiring failure on two therapies before approval for ACTH – referenced AES guideline.
- ♦ Two AES-led guideline initiatives in progress – ECOG (with AAN and ACNS) and update to the Epilepsy Surgery guideline (with AAN and American College of Neurosurgeons). Work is also in progress on AAN-led Joint Guideline on Women and Epilepsy. A Laser Interstitial Thermal Therapy insurance denial appeal guidance was posted.
- ♦ We submitted joint comment with NAEC on issues specific to epilepsy in CMS proposed changes to E/M coding and signed on to AMA and AAN general letters to CMS on same subject – the final rule addressed many of the concerns.
- ♦ Infantile epilepsy and refractory status epilepticus were submitted as topics in response to a PCORI call for consideration for systematic review which could support an evidence-based guideline. PCORI will be moving infantile epilepsy forward for preliminary scope review.
- ♦ We submitted AES comment on ILAE draft classification of neonatal seizures. We are submitting a request to the National Uniform Claim Committee to have epilepsy code added for provider specialty.

Research

- ♦ 23 early career proposals funded (total of 86 applications) – totaling \$1,030,000 in funding (\$872,500 AES funds and \$157,500 partner funds).
- ♦ We continue to support the Susan Spencer Clinical Research Scholarship – jointly funded with AAN and EF at \$130,000 for two years. Seed grants and workshop grants were awarded totaling \$150,000.
- ♦ The AES/NINDS Epilepsy Benchmarks Stewards Committee is drafting reviews of progress and opportunities in each Area. NINDS has invited the AES committee to participate in drafting agenda for NINDS Curing Epilepsies 2020 Conference

after which new benchmarks will be drafted. A new aspect is inclusion of patient advocate input through representatives selected from ELC.

- ♦ A new Poster session was added to the annual meeting highlighting research of a diverse community.
- ♦ The research council partnered with the Fellows committee on targeted mentorship support to fellows who identify with underrepresented minorities.
- ♦ Development is underway on new and improved EpiPort online self-directed clinical research training modules and mentorship program.
- ♦ Planning is underway for a Sleep & Epilepsy workshop for spring 2019 – funded by private foundation with carryover funds from a CURE project.

Membership

- ♦ Current membership stands at 4,380, up from 4,082 at this time last year. New members to date this year total 975.
- ♦ More than 45 new FAES candidates approved

Development

- ♦ AES continues to have strong industry support, with \$1.2-million for Annual Meeting grants, sponsorships and advertising and additional program support of nearly \$700,000.
- ♦ We have achieved 100% giving participation by Board and Council chairs.
- ♦ The streamlined donor recognition cycle will cover November 1 – October 31 each year.
- ♦ AES has also received two significant bequests for endowments.

Communications

AES issues expert alerts on CBD and Epilepsy and on approval of Epidiolex and rescheduling of FDA-approved medications containing pharmaceutical-grade CBD. AES as a member of ELC signed on to Epilepsy Leadership Council policy agenda which includes support for increased research funding; support for funding for surveillance, data collection and prevention activities; and opposition to policies which limit access to care.

Chapter Reports *(continued)*

Collaboration and Partnership

AES continues as the administrative home for, and member of, Epilepsy Leadership Council. With the Epilepsy Foundation, AES is a partner in National Epilepsy Education and Awareness Collaborative, and represented at EF Research Roundtable and Learning Health Initiative. AES is a partner in the CNF Infantile Spasms Awareness Network (ISAN) and Transitions Project Advisory Committee (TPAC). With ILAE, AES partners to support the Joint Translational Task Force and is engaged in helping to secure U.S. support for placing epilepsy on the WHO Executive Committee agenda. AES also continues to support ILAE efforts for a global epilepsy research initiative in the EU.

Challenges:

AES continues to examine how we can best support all professionals in the epilepsy community to meet our shared mission of eradicating epilepsy and its consequences. Meeting the diverse needs across all areas with the best offerings possible is our greatest challenge and opportunity.

Future Plans:

AES recently updated our 2015-2020 strategic plan and will be developing a new strategic plan in fall 2019.

Officer Election Date: elections take place in the fall each year and terms begin at the December Annual Meeting

URUGUAY: Uruguayan League Against Epilepsy

Report By: Andrea Rey

Publications:

Revista Uruguaya de Epilepsia (RUE)- Vol 26 No.1 and 26 No. 2 (Aug/Dec 2018)

Summary of Activities:

Annual scientific meeting 2018- Invited conference at the University Hospital, on Seizure semiology in children and adults, by Alexis Arzimanoglou, followed by case discussions.

Participation/support to local academic activities:

1. Support to the Uruguayan Congress of Neurology,

held Nov 11-13, 2017 (Minas). Invited speakers: Fernando Cendes, Silvia Kochen. Topics: neural networks, structural and functional neuroimaging, invasive EEG recording.

2. Participation in the Uruguayan Congress of Pediatric Neurology, held Aug 29-Sep1, 2018 (Montevideo). Conference: Experience on children with refractory epilepsy in the Epilepsy Surgery Program of Montevideo (Andrea Rey).

Support regional academic activities-

Active support/participation, either by LUCE as organization or by some of its members, in the online course for primary care in Latin America (ILAE Education Commission), Latin American Summer School on Epilepsy, Epilepsy Week in Bolivia; during 2018 also participating in the ILAE-IBE Meeting in Asunción (Paraguay)

Advocacy and public outreach:

- Self-aid groups: free meetings every other week, under the guidance of a psychologist provided by LUCE. Separate groups for patients and relatives.
- LUCE as mediator and promoting actor in the development of an institutional agreement between some academic services at the University Hospital and the National School for Police Education. Starting on 2017, this agreement allowed for the development of training courses on basic epilepsy management (among other topics).
- Latin American Epilepsy Day 2018: journey with educational material in the Rodó Park.
- Educational activity for teachers at a public primary school in Montevideo (Nov 2018)
- Educational activity In Paraguay (with Paraguay Chapter, LUCE and UCLE)

Government liaisons:

- Resuming negotiations with delegates in the Parliament regarding a Law for Epilepsy patients (LE Rodríguez).

Challenges:

- Improvement of financial performance

Chapter Reports *(continued)*

- Development of institutional website
- Sustainability of our institutional Journal (2 issues per year)

Future Plans:

- To promote an active discussion, leading to the approval of a Law on Epilepsy.
- Working close to the IBE chapter and the existing Association of parents of children with epilepsy, to achieve common goals.
- To increase the visibility of the League, improving and extending our activities devoted to the whole community.

Officer Election Date: November 12, 2017.

ZAMBIA: Zambia League Against Epilepsy

Report By: Naluca Mwendaweli

Summary of Activities:

We held two chapter meetings.

1. To discuss the way forward for the organization, set up

our own account and brain storm how to recruit more members.

2. We had a meeting to come up with our strategic plan and see how best we could work with the ministry of health. We are yet to meet with the Non-communicable diseases national al coordinator at the ministry of health and see how best we can collaborate in the fight against epilepsy

Challenges:

Difficult to hold executive committee meetings as we are in different parts of the country

Future Plans:

1. Recruit more members
2. Finalize our strategic plan
3. Improve on fundraising ventures
4. Increase awareness amongst health professionals

Officer Election Date: June, 2017

CONSTITUTION

Article I – Name

The name of this international organization, founded on August 29, 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 August 31, 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 world-wide 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 world-wide 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 By-Laws.
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, U.S.A.

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 9 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 By Laws must not contain articles inconsistent with the Constitution and By Laws of the ILAE. A copy of the Chapter’s Constitution and By-Laws must be kept in the League’s main office. Any changes in the Chapter’s Constitution and By-Laws 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

CONSTITUTION *(continued)*

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 By-Laws. 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. Executive Committee shall consist of:

1. 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.
2. The President, Secretary-General and Treasurer of the International Bureau for Epilepsy, (hereinafter called the “IBE”), as ex-officio, non-voting members.
3. The Editor-in-Chief of *Epilepsia* as a non-voting member, appointed by the voting members of the Executive Committee.

3. The Management Committee:

1. Shall consist of the President, Vice President, Secretary-General, Treasurer, and Immediate Past President.
2. The Management Committee will implement the policies approved by the Executive Committee and govern the League between meetings of the Executive Committee.
3. 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.
4. 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

CONSTITUTION *(continued)*

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.

5. 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.
6. 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.
7. 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.
8. 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.
9. 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.

10. The Executive Committee shall have the power to formulate at any time By-Laws 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.
11. 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 the Chair to close the meeting to observers. Only delegates may speak and vote. Exceptionally

CONSTITUTION *(continued)*

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.

CONSTITUTION *(continued)*

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 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.

Bylaws

Ratified on October 02, 2011

Amended April 2012, June 2012, June 2013, May 2015,
September 2016, March 2017

351 – 750 members: 4 votes
751 – 1500 members: 5 votes
above 1500 members: 6 votes

Chapters that do not collect dues shall have one vote.

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

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 run-off shall be held between the two candidates who received the highest number of weighted votes. The candidate in the run-off that receives the highest number of weighted votes cast shall be elected. If both candidates receive the same number of votes, the candidate with the highest number of un-weighted votes will prevail. If the tie still holds after counting un-weighted votes, the candidate who had been in the Executive Committee for 8 years already will prevail. In the event that the tie still holds, the older candidate will prevail.

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;

Bylaws *(continued)*

- 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;

Bylaws (continued)

- 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. Will 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 world-wide elections and maintaining the regional requirements that pertain to the elected members of the Management Committee (article 1, item 7).
- Executive Committee: Should a vacancy involve the positions of regional chair, an election will take place according to the rules for regional elections and approved by the EC. If such rules are not available at the time of the special election, the election procedures used for the 2013 elections will be followed.
8. The Editor(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

Bylaws (continued)

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

Bylaws (continued)

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 VI- Resource- and Topic-specific Commissions and Task Force

Bylaws *(continued)*

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.
- Said final report shall be communicated to the Chapters.
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.

Said final report shall be communicated to the Chapters.

Article VII- 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.

Article VIII - Fiscal Year

The fiscal year of ILAE shall be January 1 through December 31.

Article IX- 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 X - Meetings

1. The International Congress of ILAE shall be held ordinarily every two years, in conjunction with the International Bureau for Epilepsy.
2. In the year between two International Congresses of the ILAE, the Regional Divisions of the ILAE will organize Regional Congresses with the support of the ILAE.
3. The International Congress of ILAE and the Regional ILAE Congresses will be organized with the assistance of the ILAE- designated International Director of Meetings.
4. The ILAE may sponsor or support, wholly or in part, other meetings relevant to its objectives. Such a meeting shall not be designated as an International Congress of the League.

Article XI - 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 XII- 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.

Article XIII - 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-

Bylaws *(continued)*

- organized Epilepsy Congresses and the Global Campaign, and such other matters as the ILAE and IBE Executive Committees shall consider appropriate to be delegated to consideration and decision by a JEC.
6. A proposed action by a JEC should not be in conflict with the Constitution of the ILAE and must be ratified by the two ILAE and IBE Executive Committees prior to implementation.
 7. Chairing of each JEC shall be shared equally between the ILAE and IBE Presidents, or their nominees, in a manner acceptable to both. The Chairperson of a JEC shall not have a casting (i.e., tie-breaking) vote.
 8. A quorum for a JEC shall be the presence of a majority of the members of each of the ILAE and IBE Executive Committees.
 9. A JEC may be convened at any time mutually acceptable to the Presidents of both the ILAE and IBE.
 10. To be considered by a JEC, a motion must be moved by a member of one Executive Committee, and seconded by a member of the other.
 11. Responsibility for administration, minuting etc. of JECs shall be shared equally between the Secretaries-General of the ILAE and IBE, in a manner acceptable to both.
 12. Responsibility for overseeing all financial matters considered by JECs shall be shared equally between the Treasurers of the ILAE and IBE, in a manner acceptable to both.
 13. A Joint Committee, consisting of the voting members of the ILAE Executive Committees and the Management Committee of IBE, is authorized to take actions in the name of a JEC between JEC meetings.

Such actions must:

- A. Be approved by a majority of each of the Committees of the ILAE and IBE;
- B. Be in accord with policies of both the ILAE and IBE;
- C. Involve neither Executive Committee in expenditure exceeding a sum to be set by each Executive Committee;
- D. Be notified to each Executive Committee as soon as possible;
- E. Be ratified by each Executive Committee at its next meeting.

Article XIV - 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 XV - 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.



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