



1909-2019



International League
Against Epilepsy



2019 ANNUAL REPORT

ILAE AT 110

The Changing Landscape



COVER IMAGERY



In 1909, ILAE was established as an organization during a meeting at Budapest's Hotel Bristol (*top*). During its 110th anniversary year, ILAE hosted its 33rd International Congress at the Centara Grand Hotel & Bangkok Convention Centre (*bottom*).

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President



Samuel Wiebe

The ILAE is 110 years old!

2019 marked the 110th birthday of the International League Against Epilepsy, which was founded on August 30, 1909, in the Donau room of the Hotel Bristol in Budapest. This milestone anniversary was highlighted in two publications in *Epilepsia Open*, one by [Simon Shorvon](#) commenting on the first 100 years of the League, and the other by recent [Past-presidents of the League reflecting on developments over the last decade](#).

The League's stated mission 110 years ago was to devote itself to people with epilepsy and to find means for the prevention, treatment, and rehabilitation of epilepsy. The League's current stated mission is not much different, i.e., to ensure that health professionals, patients and their care providers, governments, and the public world-wide have the educational and research resources that are essential in understanding, diagnosing, and treating persons with epilepsy (see [ILAE's Goals, Mission, and Strategy](#)).

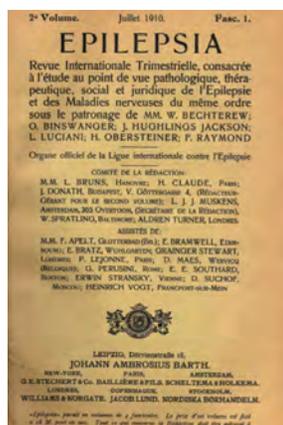
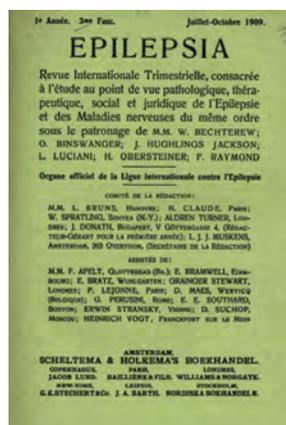


Figure 1. The quarterly journal, *Epilepsia*, becomes the official publication of the newly created International League Against Epilepsy in 1909 (From: [Shorvon, et al, "ILAE Centenary Book"](#)).

However, over the span of 110 years, the League has changed and grown much. For example, its membership now counts 122 chapters, representing 132 countries and over 17,000 people in all regions of the world—the sun never sets on the ILAE! Its tactical team encompasses over 600 of the world's

top epilepsy professionals carrying out important work in many areas. The League organizes one biennial International and six biennial Regional epilepsy congresses and supports WONOEP (The Workshop on Neurobiology of the Epilepsies), a biennial international basic science workshop on epilepsy. The League's publication portfolio has expanded from the founding quarterly journal, *Epilepsia*, in 1909 (Figure 1), to three peer-reviewed journals and a Wikipedia Project, in addition to numerous social media and web offerings. The ILAE is now indeed the world's preeminent association of health professionals and scientists working toward a world where no person's life is limited by epilepsy. In the apt words of Simon Shorvon, the League has become "[an extraordinary, complex, and multifaceted organization...very different from that envisaged by the small number of founder members who met in the Hotel Bristol in August 1909.](#)" Most appropriately, the occasion of the ILAE's 110th anniversary has been highlighted in all of the League's congresses in 2019 (Fig. 2).

The wide array of activities underway in 2019 in the League is summarized in the accompanying reports from various officers and commission leaders. Here I highlight specific aspects of the state of ILAE at the close of its 110th anniversary year:

The ILAE tactical team

- In 2019, the team of professional leaders working on specific ILAE projects around the world numbered about 600 strong.
- These top epilepsy professionals are engaged in creating ILAE reports, guidelines, and position statements, producing a myriad of epilepsy educational materials, organizing activities worldwide, establishing educational platforms, editing League journals, revamping the League website and keeping it updated, reaching out to the community, liaising with key international organizations, advocating locally and internationally, organizing congresses, and many more activities. The League is indebted to its outstanding tactical team.



Figure 2. A gathering of ILAE and IBE presidents celebrating the League's 110th anniversary during the 33rd International Epilepsy Congress in Bangkok. From left to right: Martin Brodie (current IBE president), Pete Engel (ILAE past-president), Peter Wolf (ILAE past-president), Samuel Wiebe (current ILAE president), Emilio Perucca (ILAE immediate past-president), Thanos Covanis (IBE immediate past-president), Nico Moshe (ILAE past-president), Richard Holmes (Director of Congresses and IBE past-president).

ILAE Congresses

- The highly successful 33rd International Epilepsy Congress was held in Bangkok, Thailand in June 2019. The congress is a joint ILAE and IBE event, and it showcased innovations in content and organization with more than 60 informational and research sessions, interactive talking shops, a highly successful Young Epilepsy Section (YES) program, and a dynamic package of activities for new epileptologists, including mentoring and leadership. The congress once again enjoyed the participation of our neurobiology colleagues. The WONOEPSymposium, held immediately before the Congress, focused this time on the fundamental mechanisms of what constitutes a seizure. Other important events included the launch of the Global Report on Epilepsy (highlighted below), and a hands-on Wikipedia workshop. I would like to thank the congress' Scientific and Organizing Committee and the congress office for putting this outstanding event together.

- Two Regional ILAE-IBE Congresses were held in 2019: the 5th Eastern Mediterranean Epilepsy Congress in Marrakesh, Morocco (March 2019), and the 4th African Epilepsy Congress in Entebbe, Uganda (August 2019). These congresses highlighted the needs that are most relevant to these regions, and the importance of internal and external collaborations. The organizing committees and congress office did an outstanding job in both congresses.
- For over two decades, all ILAE congresses have been organized by Chancel, a private company under the direction of Richard Holmes. As Richard moves on toward retirement, the ILAE Executive Committee decided to create its own company which will be responsible for organizing all its congresses. This process is well underway and is expected to be completed by early 2020.

The WHO Global Report on Epilepsy

Please see [World Health Organization \(WHO\) and Epilepsy](#)

- As highlighted below in Dr Alla Guekht's report, a major achievement in 2019 was the publication of the global report on epilepsy entitled "*Epilepsy: A public health imperative.*" The report, launched during the 33rd International Epilepsy Congress in Bangkok, is a World Health Organization publication produced jointly with the ILAE and its sister organization, the IBE.
- This broad-ranging report, the first of its kind, is not only a summary of the state of epilepsy worldwide, but also a blueprint for areas that require action and priorities for support. Its executive summary has been published in the six main languages of the WHO.

Re-structuring the ILAE Organization and Administration

Defining the roles and responsibilities of ILAE organizational entities

The growth and diversity of ILAE activities necessitated a set of organizational entities to support their optimal function and long-term planning. Accordingly, the various organizational entities, as well as their mandates and terms of reference were revised into the following five categories: Councils, Regional Executive Boards, Topic-oriented Commissions, Committees and Task Forces (see [Structure of ILAE Organizational Entities](#)).

In 2019, the ILAE Executive Committee approved the creation of [ILAE Councils](#). These are standing working groups, whose mandate is the oversight and coordination of specific areas, based on functions defined by the League's Mission and Strategic Plan. The councils are responsible for long- and short-term planning, policy review, and making recommendations to the Executive Committee. At the outset, the following four Councils have been created: Education Council (Chair: Ingmar Blümcke), Publications Council (Chair: Jean Gotman), Congresses Council (Chair: Helen Cross), and Global Advocacy Council (Chair: Alla Guekht). These councils replace the corresponding Task Forces. Below, you will find an initial report from each of the Councils. We wish our new Councils the best as they establish themselves in this important new role.

Appointment of an Executive Director

Another important change in the ILAE structure will be the appointment, for the first time in its history, of an Executive Director. Since its inception, managing, organizing, and coordinating all administrative and tactical work in the ILAE has been handled by its unpaid volunteers in the Executive and Management Committees, as well as members of the various organizational entities described above. The ILAE stood as a notable exception among medical professional organizations of its size and trajectory, for not having an Executive Director assisting the organization and participating in strategic planning.

The explosive growth of the ILAE portfolio of activities necessitated revisiting the ability of its volunteers to carry out

this increasingly complex package of work, and the need to recruit an Executive Director. Accordingly, the League's Executive Committee approved the appointment of an Executive Director and, during 2019, engaged a professional company to search for an individual to occupy this role. The mandate of the Executive Director includes the following: serving as chief staff executive, recommending and participating in the formulation of policies, and making decisions within existing policies as they have been approved by the Executive Committee; planning, organizing, directing and coordinating the staff, programs and activities of the League to assure that objectives are attained, plans are fulfilled, and member needs are met; maintaining effective internal and external relationships; and achieving economical, productive performance and forward-looking programming. We expect this position will commence in the second quarter of 2020.

New and Ongoing League Initiatives

Numerous initiatives are underway or commencing in 2019. Notable among them:

- The League's educational activities have consolidated under the umbrella of the [ILAE Academy](#) and the platform is expected to launch by mid 2020. Visit the ILAE Academy website to learn more (www.ilae-academy.org).
- After years of preparation and work, The [ILAE Educational Curriculum](#) was completed and published³. This competency-based curriculum has been translated into several languages and will serve as the scaffold to create a credit-based ILAE educational programme for learners around the world.
- New task forces commenced work in 2019, including Telemedicine, Ontology, and SNOMED terminology in epilepsy, among others.
- New ILAE sections were formed in 2019 to engage professionals who work within specific areas in epilepsy and who are not well represented currently. These include Nursing (Chair: Marielle Prevost-Morgant) and Social Work (Chair: Jacob Mugumbate).

Finances

- A full overview of the League's finances and a description of audited financial reports for 2018 is provided by our treasurer, Dr Helen Cross. Thanks to the tremendous work of our financial experts on the Finance Advisory Board and our Finance Committee, the League's finances were in good standing at the close of 2019.
- The endowment reached its goal in 2018 and it is serving its purpose of supplementing funds to our budget when needed, in accordance with a formula that ensures continued financial good health.

In summary, 2019 has been a remarkable 110th anniversary year for the League, thanks to the hundreds of people in its organizational and tactical teams, and to the thousands of professionals around the world who work tirelessly to improve the lives of those who suffer from epilepsy. To them all, the League owes a debt of gratitude.

Samuel Wiebe,
President

Treasurer



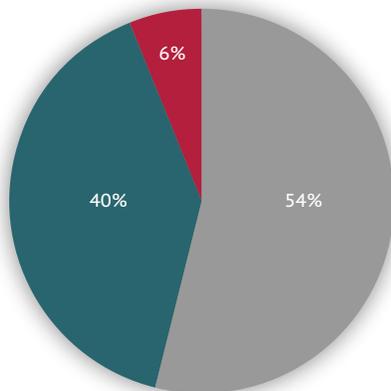
J. Helen Cross

This past year, ILAE reached a milestone that has been a work in progress since 2011: With the sound advice and financial expertise of a group of non-medical volunteers comprising the Financial Advisory Committee, ILAE reached its endowment goal of \$20 million. We were able to achieve this goal during a period when we reduced registration fees for congresses, especially for junior members, and maintained support for our commissions and task forces despite steadily decreasing congress surpluses. The earnings of the endowment will be used to provide revenue during lean years and to fund new projects and initiatives in better years. This endowment provides the League with security and sustainability.

The charts below illustrate the audited financials for 2018. The 2018 regional congresses held in Vienna, Bali, and Costa Rica generated 54% of the 2018 revenue, which included registrations, exhibits and sponsorship. Revenues from our publications account for most of the administrative revenue.

Operational Revenue 2018

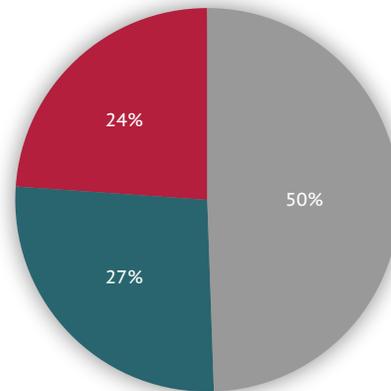
- Administration
- Commissions
- Congresses



The corresponding expenses are charted below. The 2018 congresses ended with a slight surplus while the larger administrative surplus supported the activities of the commissions and task forces. The final operating surplus for 2018 was approximately \$312,000. However, the 2018 stock market ended the year with a downturn, resulting in an investment loss of approximately \$1 million. Thus, the final result for 2018 was a loss of approximately \$600,000.

Operational Expenses 2018

- Administration
- Commissions
- Congresses



Fortunately, the stock market was very strong and robust in 2019, and, as previously mentioned, allowed us to reach our endowment target of \$20 million. We have since revised our overall spending policy to allow using the earnings from this fund for future projects supporting our mission. In 2019, there was an increase in administrative revenue, primarily with our distance learning courses and journal royalties. Although we underspent in both the administrative and commission categories, there were new expenses related to the planned appointment of an Executive Director, the continued investment in education, and the creation of a new ILAE company that will organise our ILAE congresses. We will therefore end the year with an operational deficit that is much less than originally budgeted. However, factoring in the strong 2019 investment earnings, the final 2019 result will be a surplus of approximately \$2 million.

In 2020, the ongoing administrative changes continue to impact the budget. The educational investment of the past few years will culminate with the launch the ILAE Academy, which will begin to generate revenue in 2020. The newly appointed Executive Director will address widening our horizons and exploring other ways of generating income for the future. Additionally, the newly created Congress Council and the Executive Director will address changes to our congress format, ensuring that our congresses continue to operate at a surplus, while addressing the needs of our regional and international communities.

Treasurer *(continued)*

We are grateful to the Commissions and Task Forces for the ongoing work toward meeting our mission and goals. The budgets submitted for 2020 took careful thought and planning. We were able to approve a substantial portion of the requested budgets and hope in the future to consider additional projects. As ever, we are grateful to the budget committee whose members work hard over the holiday season to review all budgets, as well as to our group of financial volunteers who advise us through the Financial Advisory Committee.

Report by Helen Cross and Donna Cunard.

J. Helen Cross,
Treasurer

Vice President



Alla Guekht

Key activities in 2019 focused on promoting epilepsy as the public health priority at the level of the WHO and Member States, fostering the collaborative efforts in epilepsy, increasing engagement of the Member States, and collaborating with non-state actors. Following the landmark World Health Assembly (WHA) resolution on the global burden of epilepsy, further efforts were needed in order to reduce major gaps in awareness, diagnosis, and treatment of people with epilepsy throughout the world, combat stigma and discrimination, and ameliorate the burden of the disease.

In 2019, there were several significant achievements in terms of collaboration with the WHO (I am respectfully acknowledging the contribution of the members of the Management Committee, Regional ILAE Chairs, ILAE-IBE Global Outreach Task Force members, and ILAE and IBE chapters).

Inclusion of the item on epilepsy into the agenda of the 146th WHO Executive Board (EB) meeting

In January 2019, during the 144th session of the WHO Executive Board meeting, an initiative of the Russian Federation supported by Chile, China, Indonesia and Jamaica, led to the inclusion of the epilepsy item in the agenda of the 146th WHO EB meeting, scheduled for January, 2020. The agenda item called for discussion on two key aspects: 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.

This was a strategically important accomplishment, as further actions to address the global burden of epilepsy and its health and social implications at level of the WHO were possible only after acceptance by the WHO Executive Board.

The first-ever Side Event at the 72nd World Health Assembly (WHA)

A side event at the WHA is a tremendous opportunity to highlight specific health care domains to the WHO leadership and top-level health care authorities from all over the world. The demand for the slots for side events is very high, as there are a lot of applications from the Member States and non-state actors; only the applications focused on the most important conditions and presented by several Member States or non-state actors are accepted by the WHO Secretariat.

In March 2019, the Russian Federation, one of the co-sponsors of the landmark WHA 68.20 Resolution on epilepsy, submitted an application to host the official Side Event alongside the 72nd WHA. The application was co-sponsored by Croatia, China, Honduras, Kazakhstan and Zambia, and supported by the ILAE, IBE, and the World Federation of Neurology (WFN). The joint application was successful and the slot on May 22 had been given. This meeting was the first-ever official Side Event of epilepsy alongside the World Health Assembly (Fig. 1).

At a later stage, the Side Event was co-sponsored by Colombia, Mexico, Slovenia and Tunisia, so the event was actually co-hosted by the 10 Member States (representing Europe, Asia, Latin America and Africa), and it reaffirmed their commitment to taking action to address the needs of people living with epilepsy, promote epilepsy care and research worldwide, reduce the treatment gap and fight stigma.

The event had four main objectives:



Figure 1. The side event flyer

1. To review the scope and magnitude of the burden of epilepsy globally and to identify the underlying systemic issues affecting access to UHC and essential medicines.
2. To pre-launch the Global Epilepsy Report and to discuss the key strategies for strengthening leadership and governance in epilepsy, facilitating

Vice President *(continued)*

a comprehensive health care response, eradicating stigma, and enhancing prevention and research in epilepsy.

3. To learn from the experiences of Member States that have implemented demonstration projects to improve epilepsy care and access to anti-seizure medicines.
4. To strengthen Member States commitment to develop a plan of action to address epilepsy as a public health priority.

The side event was chaired by Prof Evgeny Kamkin (Deputy Minister of Health, Russian Federation), Prof Shichuo Li (China), Dr Svetlana Akselrod (UN Inter-Agency Task Force on NCDs & Global Coordination Mechanism on NCDs, WHO), and Prof Alla Guekht (ILAE). The event began with opening remarks from the Chairs, followed by statements from China (Shichuo Li), Croatia (Silvio Basic), Kazakhstan (Leila Dairbaeva), Tunisia (Chahnez Triki), and Zambia (Sharon Kapambwe) (Fig.2). Dr Neerja Chowdhary then spoke on behalf of the WHO Department of Mental Health, followed by the non-state actor representatives: ILAE given by Prof Alla Guekht, ILAE Vice President; WFN on behalf of Prof William Carroll, WFN President (presented by Alla Guekht in her capacity as the WFN Elected Trustee); and IBE by Mary Secco.



Figure 2. Chairpersons and speakers of the Side Event on epilepsy at the 72nd World Health Assembly

In total, there were more than 120 attendees at the event, representing

39 different countries across all six WHO regions: Algeria, Bhutan, Botswana, Canada, China, Colombia, Croatia, Eritrea, Ethiopia, Germany, Ghana, Guyana, Honduras, Iraq, Kazakhstan, Kuwait, Lebanon, Libya, Madagascar, Malta, Mexico, Netherlands, Oman, Palestine, Philippines, Russia, Saudi Arabia, Slovenia, Solomon Islands, South Africa, Sri Lanka, Sudan, Switzerland, Thailand, Tunisia, United Kingdom, United States, Yemen and Zambia (Fig. 3).

There was also diverse attendance from the public sector, UN, non-governmental organizations (NGOs), and academia.

Figure 3. The packed conference hall of the epilepsy side event



The side event had excellent attendance and provided a platform for discussing the important challenges faced

by countries in prioritizing epilepsy, as well as the innovative solutions and lessons from around the world. It served as an opportunity to scale up the Member States' political commitment toward addressing the gaps in epilepsy care, and moving forward with commitment to action from the hosting countries and those in attendance. Member States and other attendees were made aware of the launch and upcoming availability of the first Global Epilepsy Report, *Epilepsy: A public health imperative*. The participants unanimously acknowledged the need for a global action plan for epilepsy.

The side event had been highlighted in the WHO social media. Interviews with Prof Evgeny Kamkin (Deputy Minister of Health, Russian Federation), Alla Guekht, ILAE Vice-President and Mary Secco, the IBE Secretary-General can be found at https://www.who.int/mental_health/neurology/epilepsy/report_2019_videos/en/.

Preparation and launch of the Global Report on Epilepsy: A public health imperative

This document is the first global report on epilepsy and the product of a long-standing collaboration between WHO, ILAE and IBE; it is an important milestone in encouraging countries to prioritize epilepsy in public health agendas. Fifty-nine epilepsy experts and 38 reviewers contributed to the Report, which also incorporated the results of the survey with participation of the majority of the ILAE and IBE chapters. A complete list of all of the contributors can be found in the acknowledgment pages of the final report.

The report, "*Epilepsy: A public health imperative*," presents a comprehensive picture of the impact that the condition has

Vice President *(continued)*

on people with epilepsy, their families, communities, and society. The report highlights epilepsy as a public health priority, and strongly encourages investment in reducing its burden. Special attention is paid to the prevention of epilepsy, highlighted as an urgent unmet need. Effective interventions for prevention are noted in the report and delivered as a part of broader public health responses in maternal and newborn health care, communicable disease control, injury prevention, and cardiovascular health. The report is a global call for action to combat stigma, change legislation, and address the gaps in epilepsy knowledge, care, and access to safe and affordable anti-seizure medicines around the world. A pressing need for increased investment in research is highlighted, as well as the importance to address the burden of epilepsy through integration in primary health care, ensuring that all people with epilepsy have access to quality and affordable care.

The report was launched during the 33rd International Epilepsy Congress in Bangkok (Thailand) (Fig. 4 A, B). The special session was chaired by the ILAE and IBR Presidents, Sam Wiebe and Martin Brodie, and directors of two WHO departments - Susan Aktselrod and Devora Kestel. Tarun Dua (WHO) gave an overview of the Global Report and the WHO perspective; Alla Guekht (ILAE) addressed the role of the Report in improving epilepsy care and research, Mary Secco (IBE) focused on improving the social condition of people with epilepsy, and Susan Akselrod (WHO) presented the multisectoral approach in epilepsy. The interview about the launch of the Report is [available on YouTube](#).



Figures 4A & 4B. Launch of the Global Report on epilepsy in Bangkok

The delegates at the 33rd International Epilepsy Congress were given a copy of the 12 page executive summary when they registered. Copies of the 160 page full report were distributed at the launch of the Report, ILAE and IBE General Assemblies, and the Chapter Convention. The executive summary has been translated into the six official WHO languages – Arabic, Chinese, English, French, Russian and Spanish. It is available on the WHO, ILAE and IBE websites.

A special session, entitled WHO-ILAE-IBE Global Report on Epilepsy: “Epilepsy: A Public Health Imperative” was organized at the AES meeting in Baltimore in December, with participation by the ILAE, IBE, and AES leadership. The session was very well attended; the introduction/welcome was given by Sam Wiebe (ILAE) and Devora Kestel (WHO); the speakers – Alla Guekht, Aristeia Galanopoulou, Helen Cross, and Nathalie Jetté – presented the overview of the Global Report, and its impact on epilepsy research and care, with the focus on international collaboration and implementing the Report in North America. The panel discussion addressed the burden of epilepsy, strategies for improvement epilepsy prevention, research and care, and the need for a Global Action Plan for epilepsy (Fig. 5).



Figure 5. The panel discussion at the session, “WHO-ILAE-IBE Global Report on Epilepsy: Epilepsy: A Public Health Imperative” at the AES

Another session at the AES Annual Meeting, with participation from the members of the ILAE and IBE executives, leadership of the Global Outreach task force and representatives of many ILAE and IBE chapters, focused on the implementation of the report and the mobilization of all the stakeholders, in order to support the epilepsy agenda at the 146th WHO Executive Board Meeting (Fig. 6).

Collaboration with the WHO European Office for the Prevention and Control of Non-communicable Diseases (NCD Office)

Non-communicable diseases (NCD) are one of WHO's priorities; the significant comorbidity between epilepsy and NCDs is well-known, and the synergy in addressing major NCDs and epilepsy is essential for raising national capacity, enhancing leadership, promoting intersectoral action, and enabling countries to adopt best practices and use international materials. In light of this synergy and collaboration between the European NCD Office, the conference, “Multidisciplinary Strategies to Prevent and Combat Brain Diseases” was organized in Moscow on November 28-29, 2019, followed by the meeting and discussion in the Moscow Research and Clinical Center for Neuropsychiatry within the discussion of the ongoing collaborating projects on comorbidity of epilepsy and mental disorders, epidemiology of epilepsy, etc. The conference was an important step in raising the profile of epilepsy at

Vice President *(continued)*



Figure 6 The meeting at the AES

the WHO and the Member State level in preparation for the 146th WHO Executive Board meeting, as well as for strengthening the collaboration between the ILAE, and the World Federation of Neurology and the European Academy of Neurology, as the representative of the Ministry of Health and the leading international neurological organizations – WFN, EAN, ILAE – participated in this event. The international faculty of the conference was truly excellent, and the meeting was attended by more than 500 doctors and healthcare authorities from Russia, Belarus, and Kazakhstan (Fig. 7-10).



Figure 7. Opening ceremony of the conference, “Multidisciplinary Strategies to Prevent and Combat Brain Diseases”



Figure 8. Dr. João Breda – head of the European Office for the Prevention and Control of Noncommunicable Diseases – at the opening ceremony.



Figure 9. At the conference, “Multidisciplinary Strategies to Prevent and Combat Brain Diseases”



Figure 10. Epilepsy experts (W. Allen Hauser (USA), W. Curt La France (USA), and Ettore Beghi and Nicola Specchio (both from Italy) at the post-conference meeting in the Moscow Research and Clinical Center for Neuropsychiatry.

WHO Mental Health Forum (WHO MH Forum)

The primary focus of the 2019 WHO MH forum was on, “Enhancing Country Action on Mental Health and Developing an Integrated Approach to Brain Health”. The landmark political declaration about Universal Health Coverage at the United Nations General Assembly, where heads of state reaffirmed their commitment to spending on essential health services to cover a billion more people, was highlighted. Epilepsy represents one of the important areas of the MH Forum. The Global Epilepsy report had been presented at the MH Forum and distributed among its participants. The forum was attended by approximately 300 delegates, including 72 country representatives from 49 Member States. It gave a unique opportunity to have face-to-face discussions with representatives from the Ministries of Health and Permanent Missions, in order to promote epilepsy as a public health imperative and highlight the need

for the Action Plan for Epilepsy. It was clearly presented in the Statement from the Russian Federation (made by Alla Guekht), as well as during the panel discussion on brain health, where the importance of personalized and multidisciplinary care in epilepsy was emphasized (Fig. 11, 12).



Figure 11. Speaking at the WHO MH Forum.



Figure 12. Panel discussion at the WHO MH Forum.

Scaling up epilepsy as the public health imperative at important UN/WHO events

On September 23, Alla Guekht attended the UN High-Level Meeting, "Moving Together to Build a Healthier World," where the Declaration on Universal Health Coverage

was adopted. At several events during the UN High-Level Meeting, the importance of addressing epilepsy in achieving universal health coverage with access to quality services and effective, affordable essential medicines had been noted. The need to scale-up quality interventions and services for people with epilepsy was underlined. A number of copies of the Global Epilepsy Report were distributed among the participants of the UN High-Level Meeting.

From September 16-19, Alla Guekht attended the RC69 session of the WHO regional committee for Europe. One of the priorities of the session was "Promoting health equity in the WHO European Region." It was noted that there is a need to ensure everyone's access to integrated services that support health equity. Specific reflections focused on the need for a multisectoral approach to address health equity based on evidence; the importance of taking gender equality into account and addressing the gender bias in health; and the importance of encouraging close collaboration with local authorities to deliver health equity. This meeting was attended by approximately 300 participants, including over 60 high-level healthcare authorities and representatives of more than 44 non-state actors. A copy of the global epilepsy report was presented to a number of Ministers/Deputy Ministers of Health, scaling up epilepsy as a public health imperative and highlighting the need for an Action Plan for Epilepsy. This meeting also was very productive in strengthening collaboration with the World Federation of Neurology and European Academy of Neurology.

Advancing the Epilepsy Agenda at the Ministerial Level

In partnership with the Italian League Against Epilepsy (LICE) and the leadership of Bambino Gesù Hospital (special thanks to Prof Federico Vigevano and Dr Nicola Specchio), epilepsy was included as one of the key items of the high-level collaboration and memorandum of understanding between the Ministry of Health of the Russian Federation and the Department of Health and Welfare of the Vatican City State. Extensive preparation preceded the official signing of this document, including a meeting at the Russian Ministry of Health, and numerous discussions in the Moscow Research and Clinical Center for Neuropsychiatry.

Vice President *(continued)*



Figure 13. Visit of the Italian delegation to the Russian MoH.



Figure 14. Left to right, Dr. Renat Akjigitov, Deputy Director, Moscow Research and Clinical Center for Neuropsychiatry; Dr. Nicola Specchio, Head of the Rare and Complex Epilepsy Unit, Department of Neuroscience, Bambino Gesù' Children's Hospital; Prof. Bruno Dallapiccola, Scientific Director of Bambino Gesù Children's Hospital; Prof. Alla Guekht, Director, Moscow Research and Clinical Center for Neuropsychiatry; Prof. Federico Vigeveno, Director of the Department of Neurosciences, Bambino Gesù' Children's Hospital; Mr. Salvatore Alessandro Cristaldi, Head of Communication & International Activities, Bambino Gesù' Children's Hospital.

The memorandum of understanding between the Ministry of Health of the Russian Federation and the Department of Health and Welfare of the Vatican City State was officially signed on July 4, 2019 in Rome at the San Paolo seat of "Bambino Gesù" by Msgr. Paolo Borgia, assessor for general affairs of the Secretariat of State of the Holy See, and by Prof. Veronika Skvortsova, Minister of Health of the Russian Federation (Fig. 13-15). The signing of the memorandum

for cooperation in the field of healthcare and the visit of the Minister of Health Skvortsova to the Paediatric Hospital of the Holy See formed part of the activities on the occasion of the visit to Rome by the President of the Russian Foundation, Vladimir Putin. This event was highlighted by international press ([Vatican News](#); [TASS, Russian News Agency](#); and [Holy See Press Office Bulletin](#)).

On the next day, the delegation of the ILAE, LICE, the Italian Epilepsy Foundation, and other patient organizations in epilepsy visited the Italian Ministry of Health and had a productive discussion with one of the leading healthcare authorities, promoting epilepsy as a public health imperative and highlighting the need for the support of epilepsy actions at the level of the WHO (Fig. 16).



Figure 15. Signing of the memorandum of understanding between the Ministry of Health of the Russian Federation and the Department of Health and Welfare of the Vatican City.



Figure 16. The visit of the Italian Ministry of Health and presentation of the Global Report on Epilepsy.

Vice President *(continued)*

ILAE Profile as the Non-State Actor in the official relations with the WHO

In 2019 the WHO reconsidered the list of non-state actors with which it is in official relations. A number of reports and documents were updated and submitted for evaluation by the WHO Secretariat. (Special thanks to Priscilla Shisler and Donna Cunard for their kind assistance).

I am pleased to announce that the ILAE was approved again as a non-state actor of the WHO (the procedure started in 2019, but the decision had been made during the 146th WHO EB meeting in February 2020). The ILAE updated profile as a non-state actor in the official relation with the WHO is publicly available on the [WHO Register of non-state actors](#).

The fruitful collaboration with the World Federation of Neurology (WFN), European Academy of Neurology (EAN) and the World Stroke Organization (WSO) continued to expand in 2019. The WFN extensively supported the ILAE at the 144th WHO EB Board and the WFN, and the EAN addressed the WHO Secretariat with the request to include epilepsy items in the 144th WHO EB Agenda. Joint efforts in prevention and treatment of the post-stroke epilepsy are being implemented in the program of WSO-ESO conferences.

As the Management Committee liaison, I served on several commissions, including the board of ILAE-Europe, the Psychiatry Commission, and the Epilepsy and Driving TF; Global Outreach has been already acknowledged. Please see reports of these commissions.

Report by Alla Guekht



Figure 17. Meeting with Susan Akselrod, WHO Assistant Director-General; Devora Kestel, Director of the WHO Department of Mental Health and Substance Abuse and key officers of the department; Alla Guekht; and the WFN President, William Carroll

International Director of Meetings



Richard Holmes

In the calendar year 2019, the Congress team managed the 5th East Mediterranean Epilepsy Congress, the 33rd International Epilepsy Congress, and the 4th African Epilepsy Congress.

These congresses had a total of 2,219 attendees, 342 speakers and Chairs, with 1,014 abstracts received, and 82 bursaries awarded.



5th East Mediterranean Epilepsy Congress, Marrakech, Morocco
7-9 March 2019

The organising committee, chaired by Chahnez Triki (Tunisia) and Hassan Hosny (Egypt), comprised six members. The venue was the Hotel Les Jardins de l'Agdal. There were 140 attendees and 34 countries were represented.

Congress programme:

- The programme comprised 19 sessions, with 45 speakers and Chairs.
- The programme was created by the Scientific and Organising Committee, incorporating proposals submitted by ILAE and IBE Chapters, regional boards, commissions, committees and task forces. Main session topics: 'Aetiologies of acquired epilepsies', 'Neural networks in epilepsy', 'Diagnostic investigations in epilepsy', 'Living with epilepsy', 'Relevance of EEG & MRI abnormalities in children with epilepsy', 'Mortality in epilepsy - an under-recognised problem', 'Updates in the drug treatment of seizures and epilepsy', 'Surgery in epilepsy'.
- Two interactive Teaching Courses on 'How to design a project and publish the results' and 'EEG', took place on the first day, as well as two courses francophone d'épilepsie on 'Classification' and 'Video EEG'.
- The Young Epileptologists Session (ILAE-YES),

which was geared towards young epileptologists in the region, was very well received.

- Morning sessions on video cases were scheduled on Friday and Saturday mornings.
- Five abstracts were selected for oral presentation in a Platform Session.
- The Social Symposium took place on the final day of the congress and was open to local PWE and lay people. It was deemed a great success by all who participated in it.
- 61 abstracts were received and nine bursaries were awarded.



33rd International Epilepsy Congress, Bangkok, Thailand
22-26 June 2019

The organising committee, chaired by Samuel Wiebe (Canada), Martin Brodie (Scotland) and Anannit Visudtibhan (Thailand), comprised 11 members. The venue was Centara Grand and Bangkok Convention Centre at CentralWorld. There were 1,847 attendees and 100 countries were represented.

Congress programme:

- The programme comprised 103 sessions, with 259 speakers and Chairs.
- The programme was created by the Scientific and Organising Committee incorporating proposals submitted by ILAE and IBE Chapters, regional boards, commissions, committees and task forces, as well as epilepsy experts. Main Session topics: 'Challenges and solutions in providing epilepsy care'; 'Infection, inflammation and epilepsy'; 'Improving outcomes in drug-resistant childhood epilepsy: What more can we do?'; 'Novel therapies in epilepsy: A brave new world'; 'Applied technology in the future of epilepsy'.

International Director of Meetings *(continued)*

- The Presidential Symposium: 'Predicting the future of epilepsy.'
- The scientific programme also had a wide range of Parallel Sessions, Debates, Ask the Experts sessions, Talking Shops, Teaching Sessions and Courses, among other sessions.
- Six Debate sessions were presented in a lively and stimulating format, with internationally renowned faculty discussing opposing views about controversial topics.
- For the 'Ask the Experts' sessions, delegates were asked to submit interesting cases for discussion on three topics (women's issues, treat this and diagnose/classify this) and the experts selected cases for presentation at the Congress.
- A new programme initiative, Talking Shops, were created by special interest groups. These 14 sessions covered several specialties and were designed to be informal and interactive discussions.
- The WONOEPE Symposium provided delegates with highlights of the most significant points that emerged during the 2019 WONOEPE workshop, which took place in the days before the congress.
- Award Symposia each day offered the opportunity to meet award winners, including the IBE Golden Light awardees, the winners of the ILAE Journal Prizes and the Michael Prize.
- The focus on educational sessions and courses was increased. A series of one whole-day and eight half-day Teaching Courses was offered, covering topics such as neuroimaging, EEG, diagnosis, pharmacological treatment and status epilepticus, and three early morning Teaching Courses on 'EEG Source Imaging' (theory and hands-on), and a course for neurophysiology technicians. Morning Teaching Sessions covered counselling, focal cortical dysplasia, autoimmune epilepsy and epileptic encephalopathies, and Video Sessions on generalized seizures, focal seizures and the question "is this epilepsy or not?", as well as two ILAE-VIREPA sessions.
- 61 abstracts were selected for platform presentation

in 15 sessions.

- 881 abstracts were received and 54 bursaries were awarded.

Other highlights:

- Launch of WHO-ILAE-IBE Global Report on 'Epilepsy: A public health imperative.' This is a strategic document of the WHO, the ILAE and the IBE, and its launch was a momentous occasion for the epilepsy constituency.
- Third ILAE Mentor-Mentee Programme: 20 participants.
- Fourth ILAE Leadership Development Programme: 27 participants.
- ILAE-YES activities: Talking Shop; Open Space sessions; Exhibition Stand; Yoga session; Networking event.
- IBE EpilepsyNext activities: Golden Lights Awards; Golden Light Forum; IBE Booth.
- Awards presented:
 - Lifetime Achievement Award – W Allen Hauser (USA)
 - Social Accomplishment Award – Carlos Acevedo Schwartzmann (Chile)
 - Ambassador for Epilepsy Awards
 - International Golden Lights Awards
 - Also presented: Epilepsia Awards, Epilepsia Open Awards, Epileptic Disorders Educational Prize, Harinarayan Young Neuroscientist Prize, Michael Prize



4th African Epilepsy Congress, Entebbe, Uganda 22-24 August 2019

The organising committee, chaired by Angelina Kakooza (Uganda) and Jacob Mugumbate (Zimbabwe), comprised seven members. The venue was the Imperial Resort Beach Hotel. There were 232 attendees and 37 countries were represented.

International Director of Meetings *(continued)*

Congress programme:

- The programme comprised 16 sessions, with 48 speakers and Chairs.
- The programme was created by the Scientific and Organising Committee, incorporating proposals submitted by ILAE and IBE Chapters, regional boards, commissions, committees and task forces.
- The programme covered topics that are highly relevant within the African region and further afield and provided a flavour of the latest research in the field of epilepsy.
- Session topics included: 'Treatment gap', 'Epilepsy through the ages', 'The challenges of management', 'Epilepsy, society and cultural aspects', 'Education', 'Capacity building and creating alliances in Africa', 'Prevention is better than cure', 'Current translational and clinical research – implications for patient care', 'Epilepsy in the community', 'ILAE Young Epilepsy Section (ILAE-YES) Town Hall Meeting', 'Social inclusion of persons with epilepsy'.
- There were also several focused workshops. The ILAE Commission on Pediatrics held a workshop on 'Research in children with epilepsy in Africa – current research practices and challenges to undertaking research' and the IBE organised a symposium on 'Making epilepsy a national priority in African countries'.
- An IBRO-ILAE epilepsy course took place on the day before the congress.
- 72 abstracts were received and 19 bursaries were awarded.

Future Congresses

The Congress Team is currently working on arrangements for the upcoming congresses in 2020 (11th Latin American Epilepsy Congress, Medellin, Colombia; 14th European Congress on Epileptology, Geneva, Switzerland; 1st North American Epilepsy Congress, Toronto, Canada; 13th Asian & Oceanian Epilepsy Congress, Fukuoka, Japan), as well as the 34th International Epilepsy Congress, Paris, France and the regional congresses in 2021, regional congresses in 2022, and international and regional congresses in 2022.

Report by 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, writes the monthly eNewsletter and coordinates other communications, and oversees production of 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.



Nancy Volkers supports the League as writer and communications officer. She works closely with Edward Bertram to envision, write, and edit full-length articles and podcasts for Epigraph on topics of interest to the League's members. Nancy also creates graphics for Epigraph articles and publicizes them through multiple sources, including Newswise and social media, to generate interest from the media and the public. She handles media requests and works on other communications projects to support the League.

Epilepsia



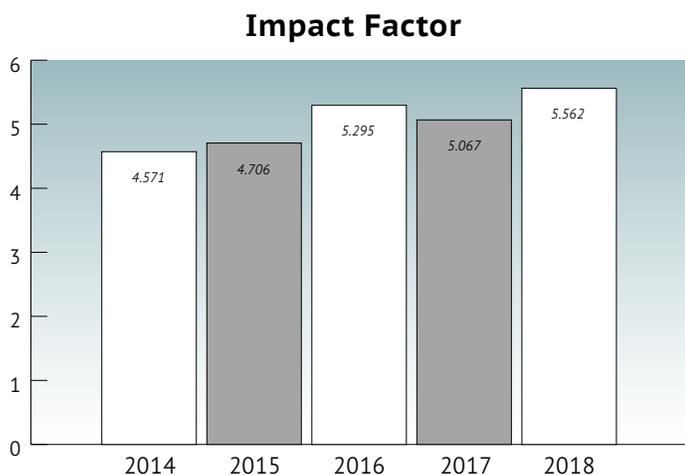
Astrid Nehlig



Michael Sperling

In 2019, *Epilepsia* had another successful year. In bibliometric terms, *Epilepsia* was ranked 25th of 199 journals in the Clinical Neurology category, had an Impact Factor (IF) of 5.562, an h-index of 168 and an Eigenfactor of 0.041. After a steady increase of the *Epilepsia* IF over five years (from 4.584 in 2013 to 5.295 in 2016), in 2017, the IF of *Epilepsia* dropped slightly 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, further raise the IF.

Evolution of the impact factor over the last five years



Volume 60 (calendar year 2019) comprised 2,764 printed pages and 165 e-only pages, which included twelve regular monthly issues.

The following supplements were also published:

- ♦ **S1: Special Issue: Epilepsy and Perampanel: Asian Perspective.** Publication of this supplement was supported by Eisai Co., Ltd. Guest Editors: Eugen Trinkka and Byung-In Lee, 67 pages.

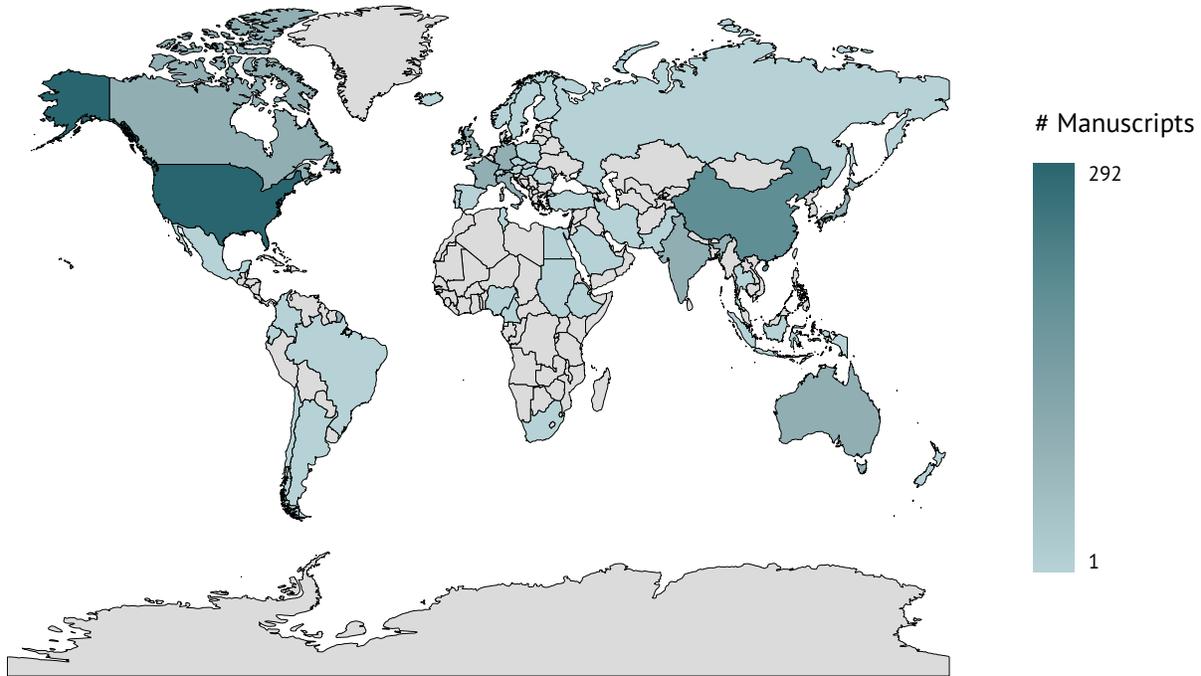
- ♦ **S2: Special Issue: Abstracts of the 13th International Congress on Epileptology,** Bangkok, Thailand, 26-30 June 2019, 225 e-only pages.
- ♦ **S3: Dravet syndrome and other channel related encephalopathies,** Guest Editors: Renzo Guerrini, Helen Cross, Rima Nabbout, and Bernardo Dalla Bernardina, 91 pages.

Manuscripts submitted to Epilepsia - 2019

MANUSCRIPT TYPE	ORIGINAL
Brief Communication	181
Commentary	6
Controversies	1
Critical Review - Invited Commentary	53
Editorial (for Editorial Office use only)	4
Executive Summary	2
Full-length original research paper	847
Letter	28
Special Report	3
Supplement Article	12
TOTAL	1137

Original Papers received - 95/month

Epilepsia Submissions 2019



Epilepsia received submissions from 63 countries in 2019.

Accept-Rejection rates are listed in terms of number of manuscripts submitted and accepted/rejected for several categories of papers published in the journal. Submission years of 2018 and 2019 are listed below. We included 2018, as all papers submitted have received a final decision. In submission year 2019, *Epilepsia* has approximately 10% of submitted papers without a final decision as of this report.

Accept-Rejection rates – 2018 submissions

2018 - All Manuscripts Submitted

DECISION	# MANUSCRIPTS	PERCENTAGE
Accept	258	23%
Reject (Direct and after review)	863	76.9%
Other	2	0.2%
TOTAL	1123	100%

2018 - Full Length Original Research

DECISION	# MANUSCRIPTS	PERCENTAGE
Accept	189	22.6%
Reject (Direct and after review)	646	77.3%
Other	1	0.1%
TOTAL	836	100%

2018 - Full Length Original Research

DECISION	# MANUSCRIPTS	PERCENTAGE
Accept	24	11.6%
Reject (Direct and after review)	183	88.4%
TOTAL	207	100%

2018 - Critical Review – Invited Commentary

DECISION	# MANUSCRIPTS	PERCENTAGE
Accept	14	42.4%
Reject (Direct and after review)	19	57.6%
TOTAL	33	100%

2018 - Critical Review – Invited Commentary

DECISION	# MANUSCRIPTS	PERCENTAGE
Accept	14	42.4%
Reject (Direct and after review)	19	57.6%
TOTAL	33	100%

Accept-Rejection rates – 2019 submissions*

*Please note that these numbers represent papers submitted in 2019 with a final decision

2019 - All Manuscripts Submitted

DECISION	# MANUSCRIPTS	PERCENTAGE
Accept	213	18.7%
Reject (Direct and after review)	827	72.7%
No final decision	94	8.3%
Other	3	0.3%
TOTAL	1137	100%

2019 - Full Length Original Research

DECISION	# MANUSCRIPTS	PERCENTAGE
Accept	135	15.9%
Reject (Direct and after review)	637	74.9%
No final decision	75	8.8%
Other	3	0.4%
TOTAL	850	100%

2019 - Brief Communications

DECISION	# MANUSCRIPTS	PERCENTAGE
Accept	18	10%
Reject (Direct and after review)	151	83.4%
No final decision	12	6.6%
TOTAL	181	100%

2019 - Critical Review - Invited Commentary

DECISION	# MANUSCRIPTS	PERCENTAGE
Accept	16	30.2%
Reject (Direct and after review)	30	56.6%
No final decision	7	13.2%
TOTAL	53	100%

Epilepsia Rejection Statistics – 2018 Submissions

2018 - All Manuscripts Submitted

DECISION	# MANUSCRIPTS	PERCENTAGE
Direct Reject	304	35.2%
Direct reject w/ transfer offer EO	193	22.4%
Direct reject w/ transfer offer EPD	47	5.5%
Direct reject/resubmit	17	2%
Reject after review	193	22.4%
Reject after review w/ transfer offer EO	35	4%
Reject after review w/ transfer offer EPD	2	0.2%
Reject/Resubmit (Reviewed)	72	8.3%
TOTAL	863	100%

2018 - Full Length Original Research

DECISION	# MANUSCRIPTS	PERCENTAGE
Direct Reject	219	33.9%
Direct reject w/ transfer offer EO	140	21.7%
Direct reject w/ transfer offer EPD	28	4.3%
Direct reject/resubmit	16	2.5%
Reject after review	150	23.3%
Reject after review w/ transfer offer EO	28	4.3%
Reject after review w/ transfer offer EPD	2	--
Reject/Resubmit (Reviewed)	63	9.9%
TOTAL	646	100%

2018 - Brief Communications

DECISION	# MANUSCRIPTS	PERCENTAGE
Direct Reject	69	37.7%
Direct reject w/ transfer offer EO	52	28.4%
Direct reject w/ transfer offer EPD	17	9.3%
Direct reject/resubmit	1	0.6%
Reject after review	31	16.9%
Reject after review w/ transfer offer EO	6	3.3%
Reject after review w/ transfer offer EPD	--	--
Reject/Resubmit (Reviewed)	7	3.8%
TOTAL	183	100%

Epilepsia Rejection Statistics – 2019 Submissions*

*Please note that these numbers represent papers submitted in 2019 with a final decision

2019 - All Manuscripts Submitted

DECISION	# MANUSCRIPTS	PERCENTAGE
Direct Reject	254	34.3%
Direct reject w/ transfer offer EO	139	18.8%
Direct reject w/ transfer offer EPD	49	6.6%
Direct reject/resubmit	31	4.2%
Reject after review	184	24.8%
Reject after review w/ transfer offer EO	37	5%
Reject after review w/ transfer offer EPD	4	0.5%
Reject/Resubmit (Reviewed)	43	5.8%
TOTAL	741	100%

2019 - Full Length Original Research

DECISION	# MANUSCRIPTS	PERCENTAGE
Direct Reject	193	33.9%
Direct reject w/ transfer offer EO	103	18.1%
Direct reject w/ transfer offer EPD	40	7%
Direct reject/resubmit	21	3.7%
Reject after review	145	25.5%
Reject after review w/ transfer offer EO	27	4.8%
Reject after review w/ transfer offer EPD	3	0.5%
Reject/Resubmit (Reviewed)	37	6.5%
TOTAL	569	100%

2019 - Brief Communications

DECISION	# MANUSCRIPTS	PERCENTAGE
Direct Reject	44	32.6%
Direct reject w/ transfer offer EO	35	25.9%
Direct reject w/ transfer offer EPD	9	6.7%
Direct reject/resubmit	7	5.2%
Reject after review	26	19.3%
Reject after review w/ transfer offer EO	9	6.6%
Reject after review w/ transfer offer EPD	1	0.7%
Reject/Resubmit (Reviewed)	4	3%
TOTAL	135	100%

Most downloaded *Epilepsia* articles in 2019

Rank	Author	Article title	Volume	Issue	# of accesses
1	Elliot J	Cannabis-based products for pediatric epilepsy: A systematic review	60	1	7,591
2	Devinsky O	Long-term cannabidiol treatment in patients with Dravet syndrome: An open-label extension trial	60	2	5,066
3	Thiele E	Cannabidiol in patients with Lennox-Gastaut syndrome: Interim analysis of an open-label extension study	60	3	3,613
4	Trinka E	Epilepsy in Asia: Disease burden, management barriers, and challenges	60	S1	3,466
5	Detyniecki K	Safety and efficacy of midazolam nasal spray in the outpatient treatment of patients with seizure clusters—a randomized, double-blind, placebo-controlled trial	60	9	2,834
6	Rodenburg R	Behavioral problems in children of mothers with epilepsy prenatally exposed to valproate, carbamazepine, lamotrigine, or levetiracetam monotherapy	60	6	2,615
7	Wu C	Effects of surgical targeting in laser interstitial thermal therapy for mesial temporal lobe epilepsy: A multicenter study of 234 patients	60	6	1,819
8	Sisodiya S	Diagnostic implications of genetic copy number variation in epilepsy plus	60	4	1,783
9	Bercovic S	The Epilepsy Genetics Initiative: Systematic reanalysis of diagnostic exomes increases yield	60	5	1,763
10	Mula M	Validated outcome of treatment changes according to International League Against Epilepsy criteria in adults with drug-resistant focal epilepsy	60	6	1,657
11	Arnold J	Co-administered cannabidiol and clobazam: Preclinical evidence for both pharmacodynamic and pharmacokinetic interactions	60	11	1,606
12	Kobow K	Genomic DNA methylation distinguishes subtypes of human cortical dysplasia	60	6	1,523

Most-cited *Epilepsia* articles over the past two years

Article Title	Vol:Issue	Author Name	Citations
ILAE classification of the epilepsies: Position paper of the ILAE Commission for Classification and Terminology	58:4	SCHEFFER, I	504
Operational classification of seizure types by the International League Against Epilepsy: Position Paper of the ILAE Commission for Classification and Terminology	58:4	FISHER, R	347
Instruction manual for the ILAE 2017 operational classification of seizure types	58:4	FISHER, R	104
Interactions between cannabidiol and commonly used antiepileptic drugs	58:9	GASTON, T	63
Brain-responsive neurostimulation in patients with medically intractable mesial temporal lobe epilepsy	58:6	SKARPAAS, T	51
Defining epileptogenic networks: Contribution of SEEG and signal analysis	58:7	BARTOLOMEI, F	49
High-frequency oscillations: The state of clinical research	58:8	FRAUSCHER, B	46
Costs, length of stay, and mortality of super-refractory status epilepticus: A population-based study from Germany	58:9	STRZELCZYK, A	43
Laser thermal ablation for mesiotemporal epilepsy: Analysis of ablation volumes and trajectories	58:5	JAGID, J	42
Brain-responsive neurostimulation in patients with medically intractable seizures arising from eloquent and other neocortical areas	58:6	SKARPAAS, T	41

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.

Through the end of November 2019, there were 2,239,000 full-text downloads of *Epilepsia* content, a 17% increase over the full preceding year. In terms of circulation and readership, in 2019, 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.

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



Aristeia Galanopoulou



Dong Zhou

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Publisher

Wiley

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

Activities (2019)

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 (Brooklyn 2019, AES meeting in Baltimore 2019) to discuss the progress, strategies and action items, and to advance the quality and visibility of the journal.

Accomplishments (2019)

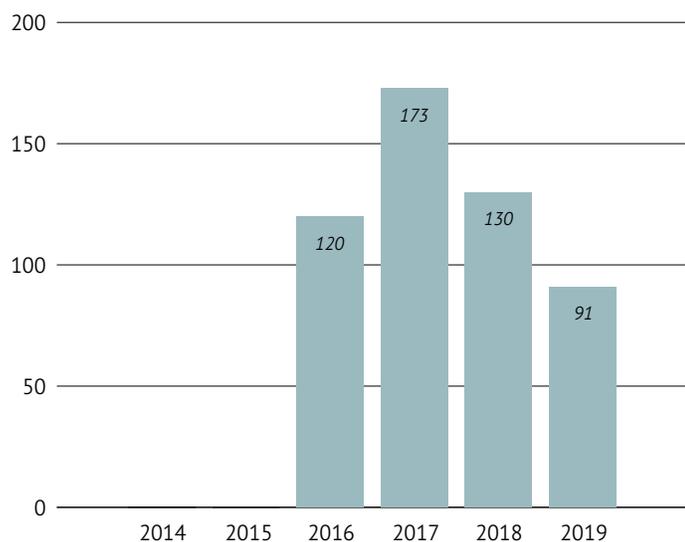
Marketing and increasing awareness of the journal: Wiley continued an extensive marketing strategy to regularly highlight the content of the journal's issues, and target both basic and clinical scientists, and epilepsy professionals through regular newsletters. Selected articles from the journal's issues are also highlighted on the ILAE website and in ILAE newsletters.

Submissions: In 2019, *Epilepsia Open* received 82 original articles, 63% of which were directly submitted to *Epilepsia Open* and 37% were transfers from *Epilepsia*.

The majority of these submissions were full-length original articles (59%) and short research articles (21%); in addition, critical reviews comprised 8% of total submissions and the rest included commentaries, special reports, and editorials. The thematic content of the submissions was largely clinical (71%). However, the increase seen in 2018 in basic and translational science was maintained in 2019 (basic: 16%, translational 13%).

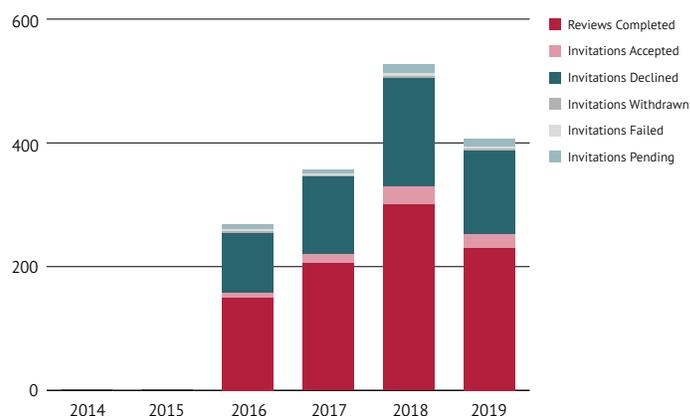
Peer review, publications: *Epilepsia Open* has engaged peer reviewers from a wide range of countries worldwide and particularly from the United States, Italy, Canada, Germany, United Kingdom, Australia, France, and

Median days from submission to online publication



Netherlands. The accept rate for new submissions was 73% in 2019, being slightly higher for transferred papers (80%) than direct submissions (67%). A continuing improvement in both peer review turnaround (see above) as well as in time from submission to first online publication (reduced to 91 days from 130 days in 2018, Figure 1) is however noted and in alignment with our efforts to accelerate good quality publications.

Reviewer engagement



The average time in peer review has dropped to 46.6 days in 2019, from 77 days in 2018, and the reviewer turnaround time ranges from 11.4 days for original papers to nine days for revisions. A continuing concern, seen widely across journals, is reviewer engagement (Figure 2) and turnarounds, largely attributed to limited volunteer time that experts can devote on reviewing articles. Plans to encourage, engage, and train a younger pool of reviewers has been discussed and is being planned.

Epilepsia Open continues to publish four issues a year, with 12-23 articles per issue. Topics range across a wide spectrum of research and health care, with most common topics being treatments, genetics, epigenetic or molecular, electrophysiology, animal models, epidemiology, and biomarkers, comorbidities, and public health issues.

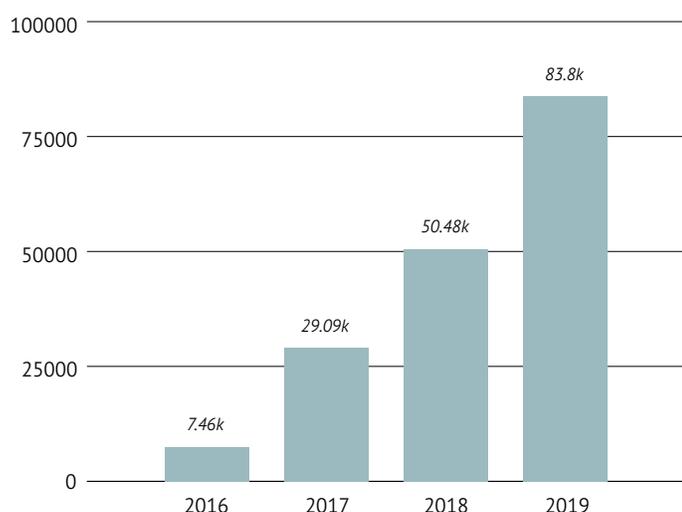
Geographic distribution of authors submitting and publishing in *Epilepsia Open*: Top submitting countries include United States (32%), Australia, Canada, Italy, United Kingdom, Japan (7-8% each), China, Germany, and Netherlands (4% each). Top publishing countries include United States, Canada, Australia, Germany, Italy, and United Kingdom.

Production: The new journal format adopted in 2019 achieved a remarkable decline in the production time. Time from acceptance to first appearance of an accepted article online is 3.5 days (from 5.5 in 2018) and time from acceptance to early view article online is 16.7 days, from 39.5 days in 2018.



Epilepsia Open Prize winners for best Clinical and Basic Science published in the journal in 2018 [Sharon Chiang (US), left, Jesus Servando Medel Matus (Mexico), right]

Download trends



Downloads: The journal has been steadily increasing its visibility and readership. Downloads of *Epilepsia Open* articles for 2019 have increased to 83,796, from 50,480 in 2018 (Figure 3). Top countries downloading articles are United States (26,094), China (8,071), India (5,248), and United Kingdom (5,023).

Epilepsia Open Prizes: Two *Epilepsia Open* prizes were awarded in 2019 to the best clinical and basic science original articles published in the journal in 2018. The best clinical science prize was awarded to Sharon Chiang (United States) for her article, [“Epilepsy as a dynamic disease: A Bayesian model for differentiating seizure risk from natural variability”](#). The prize for the best basic science article was awarded to Jesus Servando Medel Matus (originally from Mexico, currently in the United States) for his article, [“Facilitation of kindling epileptogenesis by chronic stress may be mediated by intestinal microbiome”](#). The winners presented their research and received their prizes at the International Epilepsy Congress in Bangkok (June 2019).

Citations: An increasing number of articles are now being cited, with the five top cited ranging between 20-58 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 able to receive one.

Indexing: *Epilepsia Open* is already indexed in the Directory of Open Access Journals (2017), Pubmed Central (March 2018), Scopus (December 2018), and EMBASE (November 2019). The application to ESCI (Emerging Sources Citation Index) has been submitted. There are plans to submit the applications for publication in MEDLINE and PubMed in 2020.

Recommendations for Future Work

Applications for inclusion to databases: Wiley plans to apply for MEDLINE and PubMed inclusion in 2020. We anticipate that the journal may get the first impact factor in 2021.

Marketing: Further marketing campaigns are planned to 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 with 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, and improve reviewer engagement and training of younger reviewers,
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.

Report submitted by Aristeia Galanopoulou, Co-Editor-in-Chief

Epileptic Disorders



Alexis Arzimanoglou



Sándor Beniczky

Editors-in-Chief

Alexis Arzimanoglou (France)
Sándor Beniczky (Denmark)

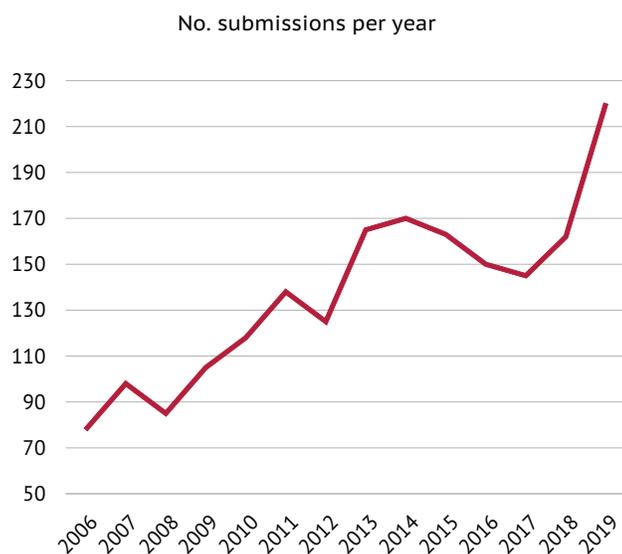
Associate Editors

Ingmar Blümcke (Germany)
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Rüdiger Köhling (Germany)
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Managing Editor

Dr. Oliver Gubbay (France)

The impact factor for *Epileptic Disorders* has increased steadily over recent years (0.942 in 2016; 1.500 in 2017), and in 2019 was listed at an all-time high of 2.052 for 2018.



Moreover, the number of submissions appears to have significantly increased over the last year to 220 (compared to 143 in 2017 and 163 in 2018).

In 2019, most submissions were from Europe (35%), followed by Asia/Australasia (33%), North America (19%), South America (6%), Middle East (4%) and Africa (3%). The countries with the most submissions were USA (15%), followed by China (10%), Japan (8%), Italy (7%), Turkey (7%), Spain (6%), Canada (4%), India (4%); Brazil (3%), Germany (3%), France (3%), other countries (<2% each).

SUBMISSIONS BY MANUSCRIPT TYPE

	2016	2017	2018	2019
Original Article	62	54	73	100
Clinical Commentary	63	69	66	92
Seminar in Epileptology/Invited	5	4	3	12
Review Article	8	7	10	6
Electroclinical Reasoning Report	4	2	5	5
Multimedia Teaching Material	2	7	4	2
Letter	6	0	1	3
TOTAL	150	143	162	220

SUBMISSIONS BY GEOGRAPHY

	2016	2017	2018	2019
Asia and Australasia	61	54	61	73
Europe	47	55	57	77
North America	27	23	23	41
South America	6	2	8	14
Middle East	9	7	7	9
Africa	0	2	6	6
TOTAL	150	143	162	220

Epileptic Disorders continues to receive predominantly Original Articles (45%) and Clinical Commentaries (42%), with an increasing number of seminar and review papers (8%). The rate of acceptance and rejection overall for 2019 was 47% and 53%, respectively. The time from submission to decision was <30 days for 41% and <90 days for 90% manuscripts.

ACCEPTED & REJECTED MANUSCRIPTS BY GEOGRAPHY	2016		2017		2018		2019	
	A	R	A	R	A	R	A	R
Asia and Australasia	14	38	17	39	15	38	23	47
Europe	28	19	26	29	36	20	38	29
North America	16	7	13	9	21	4	21	17
South America	0	5	0	1	5	6	4	6
Middle East	2	4	0	4	3	7	1	8
Africa	0	1	0	1	1	1	2	4
TOTAL	60	74	56	83	81	76	89	111

A: accepted; R: rejected

With regards to the journal site, <http://www.epilepticdisorders.com>, its publisher, John Libbey Eurotext, has continued to improve and publicize the site, and developed a new app which is now available. There has been a slight increase in the number of visitors to the site and a significant increase in the number of downloads (40% increase relative to 2018).

Content

In addition to the six editions published in 2019, a supplement was published entitled, "Encephalopathy related to status epilepticus during slow sleep: linking epilepsy, sleep disruption and cognitive impairment," edited by Guido Rubboli and Carlo Alberto Tassinari, as free access, which will also be available as a book.

In line with the educational mission of the ILAE, and in particular, with the recently developed curriculum for epileptology, a series of review articles (published as *Seminars in Epileptology*) has been planned. These will be written by invited authors who are experts in the field, and will specifically address the learning objectives of the ILAE curriculum. The first series of educational review papers will address the Level-1 learning objectives, and the first has already been published in 2019:

The aetiology of psychogenic non-epileptic seizures: Risk factors and comorbidities. *Stoyan Popkirov, Ali A. Asadi-Pooya, Roderick Duncan, David Gigineishvili, Coraline Hingray, Andres Miguel Kanner, W. Curt LaFrance Jr., Chrisma Pretorius, Markus Reuber*

Epileptic Disorders continues to publish ILAE reports and reviews as free access; in 2019, these included:

Management of epilepsy in pregnancy: A report from the International League Against Epilepsy Task Force on Women and Pregnancy. *Torbjörn Tomson, Dina Battino, Rebecca Bromley, Silvia Kochen, Kimford Meador, Page Pennell, Sanjeev V. Thomas*

Genetic literacy series: Clinical application of pharmacogenetics for adverse reactions to antiepileptic drugs. An ILAE Commission Review. *Zhongbin Zhang, Ye Wu, Nigel CK. Tan, Yuwu Jiang, and the ILAE Genetics Commission*

Indications and expectations for neuropsychological assessment in epilepsy surgery in children and adults. Report of the ILAE Neuropsychology Task Force Diagnostic Methods Commission: 2017-2021 Neuropsychological assessment in epilepsy surgery. *Sallie Baxendale, Sarah J. Wilson, Gus A. Baker, William Barr, Christoph Helmstaedter, Bruce P. Hermann, John Langfitt, Gitta Reuner, Patricia Rzezak, Séverine Samson, Mary-Lou Smith*

Roadmap for a competency-based educational curriculum in epileptology: Report of the Epilepsy Education Task Force of the International League Against Epilepsy. *Ingmar Blümcke, Alexis Arzimanoglou, Sandor Beniczky, Samuel Wiebe, the EpiEd Task Force*

Finally, in celebration of the 110th anniversary of the ILAE, review papers by invited authors were published, as free access, to mark the occasion:

Evolution of concepts in epilepsy surgery. *Jerome Engel Jr*

Antiepileptic drugs: Evolution of our knowledge and changes in drug trials. *Emilio Perucca*

Report by Alexis Arzimanoglou and Sándor Beniczky, Editors-in-Chief



Nancy Volkers

Epigraph is ILAE's online news journal. Published since 1999, *Epigraph* was refashioned mid-2018 with the addition of a full-time writer and a focus on producing frequent, long-form articles of interest to members as well as the general public.

In 2019, 28 articles were published in *Epigraph*, as well as 3 audio interviews (podcasts) with transcripts. ILAE members were alerted to new articles via email (see Fig. 1) and articles were posted on [Newswise.com](https://www.newswise.com), a free subscription website and service for medical and science-related news and announcements. Newswise has more than 40,000 subscribers, including 7,700 journalists, and the site receives 1.8 million visitors each year.

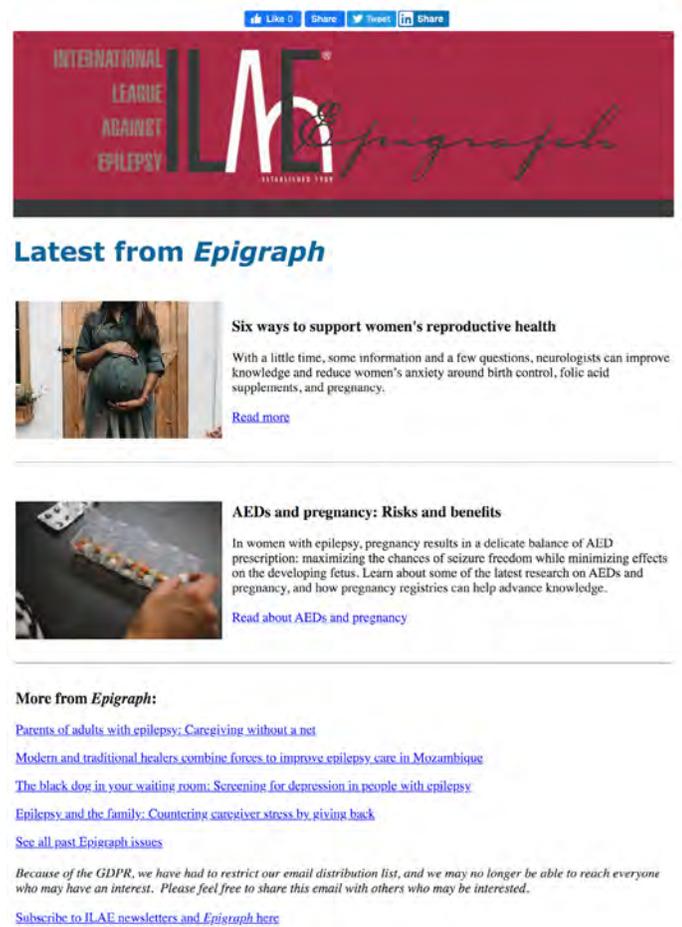


Fig. 1: Sample of an *Epigraph* email sent to ILAE's mailing list

ILAE website

In 2019, *Epigraph* articles received more than 50,000 pageviews on the ILAE website. Popular topics included the treatment of status epilepticus, the diagnosis and treatment of psychogenic seizures, an interview with Raphael Mechoulam about endocannabinoids and the history of cannabis research in epilepsy, research on the gut microbiome and epilepsy, and the effects of social anxiety on people with epilepsy.

Readers most commonly came from the United States, Mexico, India, the United Kingdom, Colombia, Brazil, Argentina, Canada, and Australia.

Newswise.com

The 31 *Epigraph* articles and podcasts published in 2019 received a collective 200,000 views on Newswise, for an average of 6,450 views per article. Several articles received more than 10,000 views. *Epigraph* articles consistently placed in the top 25% of all medical-related articles on Newswise.

Popular topics for Newswise readers included the effects of epilepsy on caregivers and siblings, psychogenic seizures, the endocannabinoid system, gut microbiota and epilepsy, the "burden of normality" faced by some people after successful epilepsy surgery, and the importance of depression screening in people with epilepsy.

Translations

Two articles were published in both English and Spanish: one on research from Colombia on social anxiety and epilepsy, and one on Paraguay's celebration of Latin American Epilepsy Week.

Adding the Spanish version of the social anxiety article increased overall views on the ILAE website by 140% and on Newswise by 76%. ILAE website analytics show that the Spanish version dramatically expanded the reach of the information (Fig. 2).

Epigraph

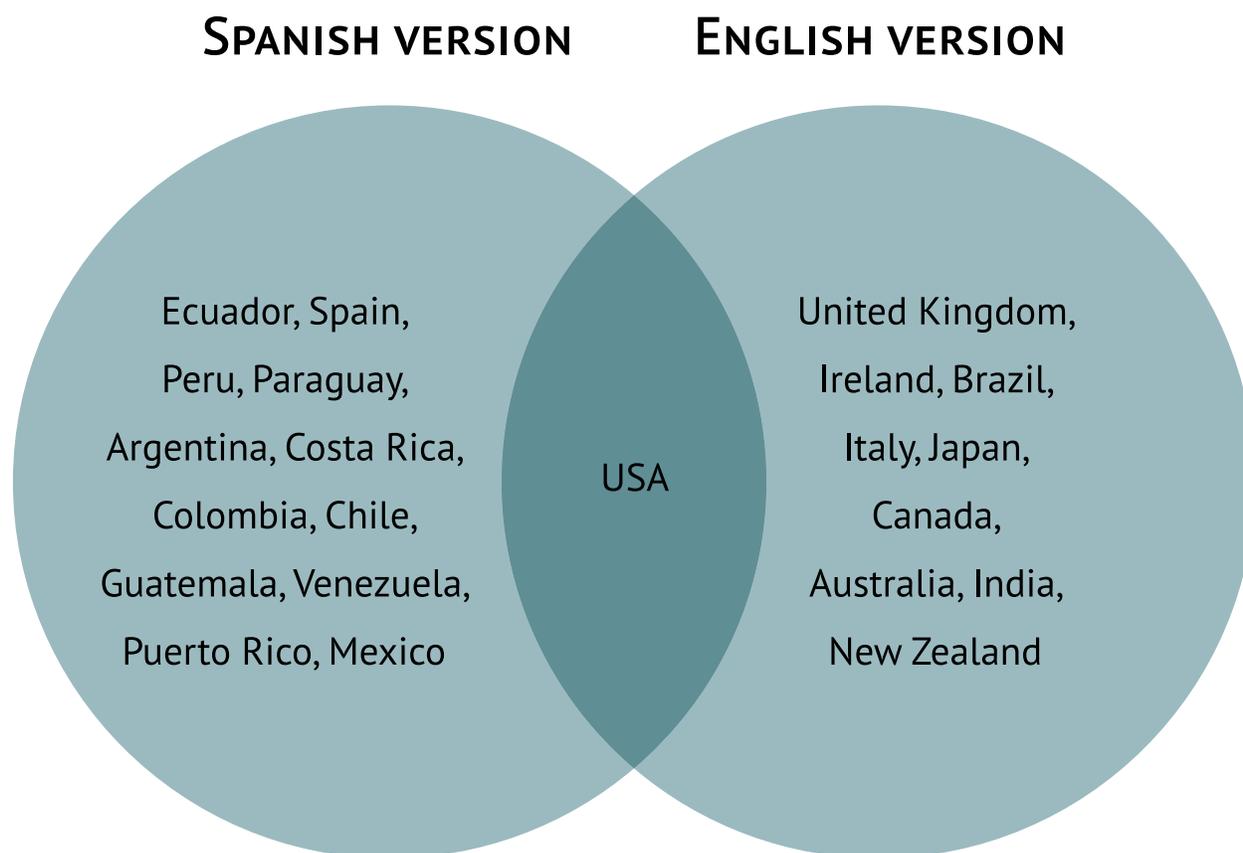


Fig. 2: Countries with 20 or more views of an Epigraph article about research in Colombia on social anxiety and epilepsy, classified by language. The English version reached readers in 10 countries and the Spanish version in 13, with very little overlap.

Adding the Spanish version of the Latin American Epilepsy Week article increased overall views on the ILAE website by 172% and on Newswise by 86%. Of note, on ILAE's website the Spanish version received 20 times the number of views from Paraguayan readers, compared with the English article.

This strategy will be used and expanded upon in the future, to provide more inclusive coverage.

Social media

Epigraph articles were shared on ILAE's Facebook and Twitter accounts to encourage readership outside the member email list and Newswise subscribers. Facebook posts accounted for 3.3% of all visits to Epigraph articles. Future social media strategies aim to increase traffic from Facebook, Twitter and Instagram.

Report by Nancy Volkers, ILAE Communications Office

The ILAE Wikipedia Epilepsy Project



Nicola Maggio

Editor-in-Chief

Nicola Maggio (Israel)

Members

Amin Azzam (USA), Wikipedian

Selim Benbadis (USA), Senior Editor

Shani Evenstein Sigalov (Israel), WikiProject Medicine Foundation

James Heilman (Canada), Wikipedia Board of Trustees

Atul Maheshwari (USA), Senior Editor & AES

Representative

Nandan Yardi (India)

Christos-Panagiotis Lisgaras (Greece)

During 2019, the ILAE Wikipedia Epilepsy Project focused on two main activities:

Increase the visibility of the project and provide support for individuals interested in participating in the Initiative.

The YES (Young Epilepsy Section) community became actively involved in the project. Through the social media network of YES, we managed to recruit interesting writers. We instructed the writers to write medical content for Wikipedia through the open-access resources developed by the Wikipedia Educational Foundation and provided online support while the authors wrote their articles. The first ILAE Wikipedia Epilepsy project workshop was held at the 33rd International Epilepsy Congress in Bangkok. We had about 30 participants at the workshop. Here, the participants had the chance to be exposed to the Wikipedia world (a lecture was delivered by Amin Azzam, MD - a Professor of Psychiatry at UCSF and a Wikipedian. The participants also had a hands-on session at the meeting, where they started to edit Wikipedia content.

Increase the amount of epilepsy-related Wikipedia entries.

Writers were recruited so that we were able to write ten new epilepsy-related Wikipedia entries. Once written, the entries underwent a rigorous peer-review system by experts in the respective fields. Only upon satisfaction of the reviewer, was the entry finally published. This content is now in process

of being uploaded to Wikipedia. In addition, five new epilepsy related Wikipedia entries are being prepared by the participants of the meeting in Bangkok.

Activities planned for 2020:

Changing the management asset of the Project.

As the project continues to grow, there is a need for better management of the people involved (writers/reviewers), together with a better planning of the Wikipedia entries to be edited and a greater involvement of social media.

Therefore, we are in the process of creating a board that will manage this Initiative. The board will be composed of the Editor-in-Chief (ILAE member), the Associate Editor-in-Chief (YES member), the Publication Editor (YES member), the Reviewing Editor (ILAE member), the Content Editor (YES member), the Social Media Editor (YES member), and the Wikipedia Hackathon Editor (YES member).

This recruitment is currently in progress and is aimed to be completed by the beginning of 2020.

Proposed Workflow of a Wikipedia Paper:

1. The Board issues a call for a topic that should be covered in Wikipedia during the next 6 months.
2. The Publication Editor recruits the Authors and sets deadlines.
3. Authors will independently decide which article to work on based on the issued topics. The authors will work on a WORD text which will be then forwarded to the Publication and Reviewing Editor.
4. Once the work has been terminated, the authors notify the Publication Editor.
5. The Publication Editor notifies the Board about the articles.
6. The Reviewing Editor will recruit a reviewer and set deadline for review of the article.
7. The Reviewer reviews the article and once terminated notifies the Reviewing Editor.

The ILAE Wikipedia Epilepsy Project *(continued)*

8. The Reviewing editor notifies the Board about the end of the review process.
9. The Content editor will post the reviewed article in Wikipedia.
10. The Social Media Editor will post the link of the article in the social media channels of the project.
11. The Content Editor will also be in charge of storing the info regarding authors/reviewers of a specific people, monitoring content in Wikipedia as well as statistics of view and update the board once a month.

Organization of the 2nd ILAE Wikipedia Epilepsy Project Workshop at the ECE 2021 in Geneva.

The Workshop is going to be held on July 6, 2020. The meeting will be structured in a similar way to the meeting in Bangkok, and it will comprise a lecture about the world of Wikipedia together with the activities that have been done up to now by the ILAE project. The core of the activity will be a hands-on session to teach how to write content for Wikipedia.

Collaboration with the Wikipedia Project Medicine:

Wikipedia Project Medicine is the official medical branch of Wikipedia that oversees all Wikipedia medical content. Our project received great visibility from this community. Wikipedia Project Medicine therefore would like to work with us in order to further improve the edited entries so that they can reach the status of featured articles. Feature articles in Wikipedia are considered to be the best articles for accuracy, neutrality, completeness and style, and therefore further changes by third parties authors to those articles is very strictly regulated.

Report by Nicola Maggio

Interactive Media



Jean Gotman

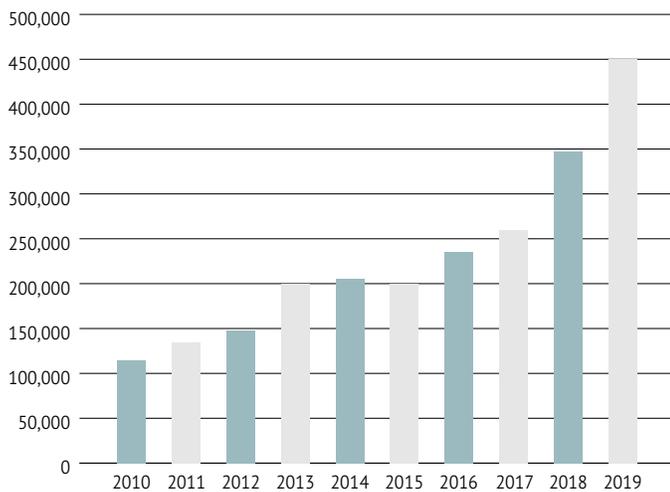


Deb Flower

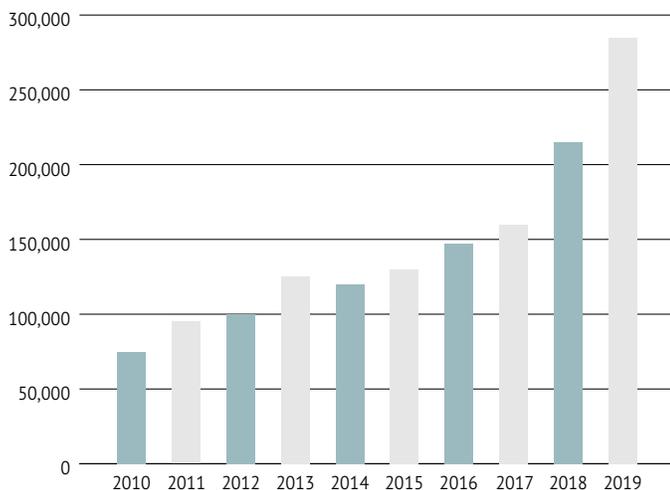
The redesigned website has now been active for two full years, and the team continues to refine and enhance its capabilities, most recently with an educational activity submission and tracking system that connects to the new ILAE Curriculum; an expanded Research section; and a specially designed page for information in Spanish.

Consistent with recent years, the number of visits and unique visitors continued to climb, with an increase of 29.8% in visits (to 450,304) and a 37.1% increase in unique visitors (to 283,483) in 2019.

Visits



Unique Visitors



While the most popular pages by far continue to be the Definitions & Classification and Guidelines landing pages, the subpages in those sections showed a large increase in views:

PAGE	TOTAL VIEWS	% INC. OVER 2018
Classification of the Epilepsies (2017)	58,516	137.9%
Definition of Epilepsy (2014)	22,825	35.9%
Operational Seizure Classification (2017)	22,166	56.3%

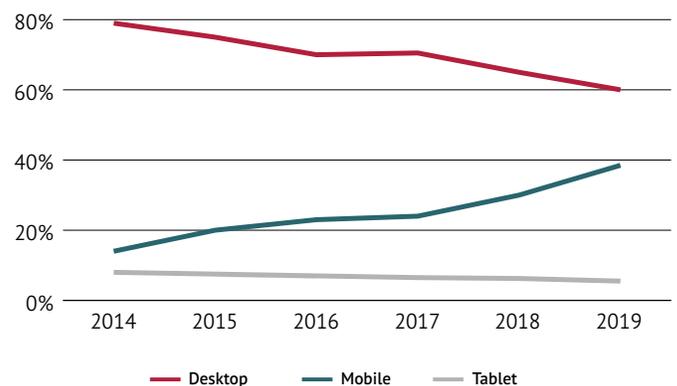
Our Guidelines and Classification reports and documents are also the most-translated; the Practical Clinical Definition of Epilepsy (2014) and the Classification of the Epilepsies (2017) are now available in 10 languages other than English, and the Operational classification and/or instruction manual have been translated into 14 languages.

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 on mobile devices. This decision is validated by the increasing proportion of visits from mobile devices, which have increased to 35.7% 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.org Device Use History



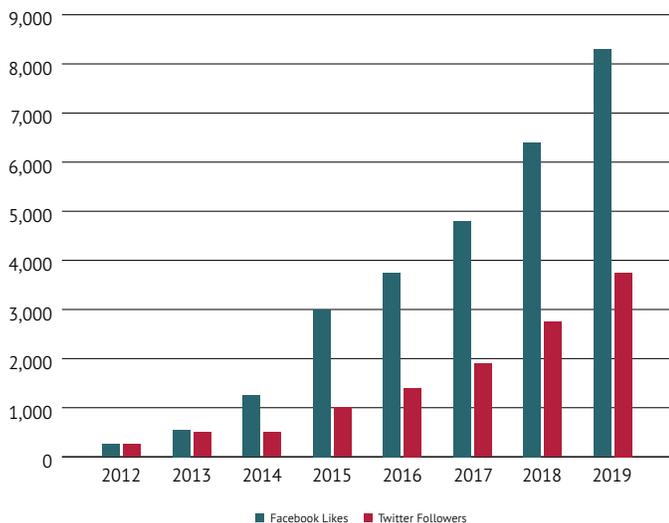
Multilingual content

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-accessed language, and visits from Spanish-speaking individuals increased by 45% to 40,815 in 2019, from 28,110 in 2018. The Spanish landing page is our sixth most-visited page and was redesigned this year to appear more like a home page. In 2019, the Spanish version of the Ketogenic Diet landing page saw an increase of 645.5% to 13,248 views.

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.

ILAE Social Media Impact



In 2019, continuing our partnership with the Young Epilepsy Section (YES), we began posting to Twitter in Arabic ([@ILAE_AR](#)) and the China Association Against Epilepsy's WeChat account, in addition to the Twitter accounts established earlier in Spanish ([@IlaeES](#)), French ([@ILAE_FR](#)), Portuguese ([@Ilae_PT](#)), Japanese ([@ILAE_JP](#)), and YES ([@yesILAE](#)). In 2019, we also established an ILAE Instagram account ([ILAE Epilepsy](#)), reflecting the preferences of the millennial generation.

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. The content of the newsletters is developed by the team, with input from the Congress office and from Wiley, to include items important to these groups, and to make sure that the most important ILAE issues receive broad distribution by these groups.

Epigraph is emailed twice monthly, and additional emails are sent when there are items of special importance.

Submitted by Jean Gotman and Deb Flower



Angelina Kakooza-Mwesige

Chair

Angelina Kakooza-Mwesige (Uganda)

Executive Board Members

Gallo Diop (Senegal), Past-chair
Mesu'a-Kabwa Luabeya (DRC), 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)

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Ghana
Guinea
Kenya
Mali
Nigeria
Rwanda
Senegal
South Africa
Tanzania
Uganda
Zambia
Zimbabwe

ILAE-Africa Goals for Term 2017-2021

1. Promote Epilepsy Awareness
2. Improve Access to Epilepsy Care
3. Conduct training in epilepsy and strengthen the education activities of ILAE-Africa
4. Foster epilepsy research in the region
5. Multiply ILAE membership in the region

Task Forces for ILAE Africa

Raising Epilepsy Awareness

Angelina Kakooza M (Uganda)
Richard Idro (Uganda)
Augustina Charway-Felli (Ghana)

Education/Training Expansion

Jo Wilmsurst (South Africa)
Ansuya Naidoo (South Africa)
Charles Hammond (Ghana)
Pierre Luabeya (DRC)

Seeking Extra Funding Through Collaborations with Other Funders

Pierre Mesu'a-Kabwa Luabeya (DRC)
Desire Tshala (USA/DRC)
Athanase Millogo (Burkina Faso)

Increasing ILAE Membership

Edward Kija (Tanzania)
Victor Sini (Cameroon)
Dr Mecky (Sudan)
Birinus Adekaibe (Nigeria)

Communication/Foster Research Agenda

Emmanuel Sanya (Nigeria)
Birinus Adekaibe (Nigeria)
Lukman Owolabi (Nigeria)
Ndeye Fatou (Senegal)

Improving Access to Care

Ndeye Fatou Ndoeye (Senegal)
Athanase Millogo (Burkina Faso)

Achievements of ILAE-Africa in past term (2019)

1. Conducted a number of Paediatric Epilepsy Training (PET) Courses across the continent in Kenya, Ghana, Tanzania, Namibia, Angola, South Africa, and Uganda.
2. Published two versions of CAA E-newsletter "Epilepsy News Africa."

3. In conjunction with local partners, conducted a series of street and video campaigns to raise epilepsy awareness.
4. Successfully held the 4th African Epilepsy Congress (AEC) in Entebbe, Uganda, August 2019.
5. Conducted a joint IBRO/ ILAE-Africa Anglophone teaching course at the 4th AEC pre-congress meeting in Entebbe, Uganda- August 2019.
6. Supported participation of African trainees in Epilepsy distance learning courses (e.g. VIREPA, San Servolo) by provision of bursaries.

Details of some of the specific activities

The 4th African Epilepsy Congress held from 22nd-24th August 2019 at the Imperial Resort Beach Hotel, Entebbe, Uganda.

The three-day congress was a joint International League Against Epilepsy and International Bureau for Epilepsy meeting that attracted a rich blend of multi-professional groups and individuals with an interest in epilepsy. The meeting was well attended with 244 participants representing 37 countries. There were 16 scientific and social sessions over three days and innovative research was presented by 50

authors of scientific/educational posters. The discussions during the congress also paved a way for opportunities to advocate for the needs of people living with epilepsy and the support groups necessary to support their care in all parts of the African region. The congress was a great success, with lively debate both in and outside the sessions, and it encouraged networking and engendered new alliances.

The Education and Training task force for ILAE-Africa organised many epilepsy related activities which are ongoing across Africa.

To highlight a few, the 2nd Annual Enugu Nigeria International Collaborative Course on Epilepsy and EEG in clinical practice was held in January. The topics covered areas ranging from the current classification and application in Nigeria to epilepsy syndrome, non-epileptic seizures, and EEG related training. Over 100 delegates attended and the full report was included in the ILAE-Africa Newsletter (Figure 1).

In February, the Ivorian Association Against Epilepsy also held a meeting with the theme of “Epilepsy of the Child: Diagnostic difficulties and care,” attended by 77 clinicians. In March, the Malian League Against Epilepsy in collaboration with the Societies of Neurology, Obstetrics and



Conference participants of the 4th AEC



Dr. Kakooza with Prof. Sam Weibe (L), President of the ILAE and Mr. Jacob Mugumbate (R), Co-Chair of the 4th African Epilepsy Congress, Entebbe Uganda.



Attendees at the 2nd Annual Enugu Nigeria International Collaborative Course on Epilepsy and EEG in Clinical Practice.

Gynaecology and Paediatrics ran a course which focused on “women and epilepsy” and “teratogeny of antiepileptics.” The need for training and expanding expertise in Africa is ongoing. Archana Patel is leading an innovative training program which has started in-country specialist training of two child neurologists in Zambia. In addition, she is supporting the training of first-line providers in the Copper Belt region, Lusaka, and Livingstone. She has also rolled out a community health worker initiative. Despite being based in the US (Boston Children’s Hospital), she has allocated significant time to upskilling the local clinicians, with the intent that the training will permit standalone expertise to become established in the country.

In April, training in EEG recording was initiated in Kumasi, Ghana, facilitated by the Child Neurology Society of America, through the motivations of Jorge Vidaurre (education outreach expert). The visiting experts focused training on two EEG technicians and six nurses.

Allied to the 4th African Epilepsy Congress in August, Pierre Luabeya coordinated a joint workshop in collaboration with IBRO. Topics included epilepsy classification, neurocysticercosis and epilepsy, as well as basic science themes of relevance for Africa. This was a superb opportunity for clinicians to mingle with basic scientists and identify areas of common interest for future projects.

Continuing the theme for training, the “Get Smarter” program is an online course promoting adult



Charles Hammond with one of his EEG technicians based in Komfo Anokye Teaching Hospital, Kumasi, Ghana.

electrophysiology skills. The coordinators are located at Groote Schur Hospital, in the adult neurology department in Cape Town, South Africa and fall under the University of Cape Town. This course has been extremely popular both for its accessibility and quality, regularly filling its 60 allocated places each year. In addition to this, the African Paediatric Fellowship Program, also originating at UCT in the department of Paediatrics and Child Health, has continued to train child neurologists. The most recent graduate (Robert Sebunya) returned to Uganda and the program itself expanded to two other universities in South Africa, which should further increase the training capacity for child neurology. The most recent innovation for the UCT arm of the APFP has been the training of technologists. In 2019, Shem Ochieng from the University of Nairobi was attached to the neurophysiology service at Red Cross War Memorial Children’s Hospital; he has returned to assist establishment of an EEG service in his centre in Nairobi. Parallel to this, UCT has established a post-graduate diploma on “Basic EEG and Epilepsy Management in Children.”

The ILAE-Africa requested \$5000 to be transferred to the VIREPA courses to expand the number of clinicians from Africa who could access these online courses.

The year 2019 was great for expanding the Paediatric Epilepsy Training (PET) courses at an international level. The course was translated into Portuguese. In September, this Brazilian faculty (faculty leads Marilisa M. Guerreiro and Ana Carolina Coan) travelled to Angola, and with the coordination of local host Dr Manuel Leite Cruzeiro, taught



Brazilian faculty running PET course in Luanda, Angola (Kette Valente, Magda Laborgue Nunes, Leticia Brito Sampaio, Laura Guilhoto, Maria Luiza Manreza, Ana Carolina Coan, and Marilisa Guerreiro).

the course for 34 local clinicians (32 pediatricians and two neurologists) as well as to two colleagues from Mozambique.

Overall, the Brazilian faculty reported that the PET course was able to fill some of the gaps regarding the knowledge of diagnosis and care of children with epileptic seizures and epilepsy. The delegates evaluated the course as good or excellent and they agreed that it fulfilled or exceeded their expectations. The exposure of the course was viewed to be so useful, especially with the content in the home language, that the Brazilian faculty have been invited to run the course in Mozambique in 2020. This extension of the PET course to Angola was supported by joint funding from ILAE and the International Child Neurology Association. The same collaboration is planned for the 2020 project.

In addition to supporting the Brazil and Angola courses, PET courses were also undertaken across Kenya (faculty leads Pauline Samia and Sam Gwer), Ghana (faculty lead Charles Hammond), Tanzania (faculty lead Edward Kija), Namibia (faculty lead Jo Wilmshurst), South Africa (faculty leads Gail Scher, Jo Wilmshurst, Elmarie van Rensburg) and Uganda (faculty leads Angelina Kakooza, Richard Idro). The course in Uganda, which was organised by Martin Chebet, occurred immediately prior to the African



Delegates from the Angola PET course, September 2019



Dr. Robert Sebunya teaching the Uganda PET course at Grand Global Hotel Kampala.



Prof. Helen Cross giving out certificates to delegates who attended the Uganda PET course at Grand Global Hotel Kampala.



Dr Martin Chebet, the Uganda PET course Director giving one of his lectures at Grand Global Hotel Kampala.

ILAE-Africa *(continued)*



Small group tutorial teaching for the Moshi, Tanzanian PET course.



Delegates and faculty for the Moshi, Tanzania PET course.

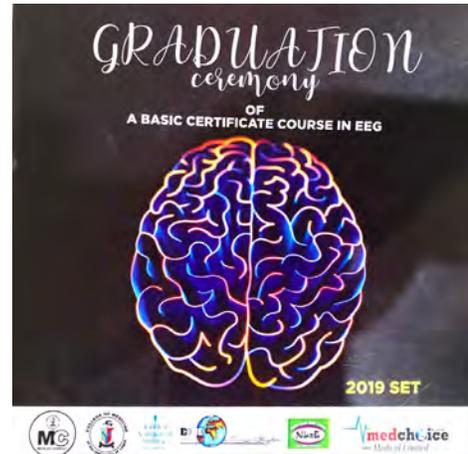
Epilepsy Congress and, as such, was an opportunity for attendees at the AEC to support the Ugandan faculty, namely Helen Cross and Jo Wilmshurst.

It is estimated that the course in 2019 alone reached some 300 health care practitioners across Africa. The need and demand for the course keeps growing with plans in 2020 to establish faculties for Zambia and Zimbabwe, as well as translating the course into French to make it accessible to develop faculties in the French speaking countries of Africa. Thanks are extended to the ongoing support and collaboration with BPNA, which developed this innovative course. Members of the BPNA have given their time to support the courses as well. For example, Mike Pike joined the faculty for the course in Windhoek, Namibia and Helen Cross for the course in Cape Town and Kampala.

Activities in other chapters

1. A health talk and street campaign against epilepsy was held in Lagos, the economic capital of Nigeria, on 4th December, and at Queens School for science students.
2. The Epilepsy Society Uganda (EPISOU), in conjunction with Next Media Productions and NBS Television, produced epilepsy raising awareness video clips which were aired on local television in English and Luganda, the local language. The public later called in to the phone lines provided to ask questions in regard to seeking health care and management of epilepsy.
3. The Nigerian League Against Epilepsy (NLAE), in partnership with the University of Lagos Teaching Hospital and the American Academy of Neurodiagnostic Technology, commenced a four-month basic certificate course in EEG. The course is meant for EEG technicians/technologists and nurses for improvement in EEG data recording and acquisition. The pioneer program was held from September to December 2019. A total of 17 students from 18 that registered, graduated from the training. The course content included six weeks of lectures and eight weeks practical on EEG acquisition and recording in any of the teaching hospitals. On-line materials were made available courtesy of the

American Academy of Neurodiagnostic Technology. The graduation ceremony took place on 29 January 2020.



Graduates of the basic EEG course and some members of faculty.

4. The Nigerian League Against Epilepsy (NLAE), in collaboration with Region's Neurosciences Center, held the 3rd annual course and workshop on Epilepsy and EEG Diagnosis between 24 and 25th January. The workshop was for meant for residents, neurologists, psychiatrists and neurosurgeons, with the focus on EEG analysis and reducing over interpretation of EEG. Faculty included Prof Aashit Shah (Virginia Tech University USA, Prof Gholam Motamadi (Comprehensive Epilepsy Center Georgetown University Hospital, WA, USA), and Dr Anyawu (EEG Lab, Carilion Clinic Virginia, USA).



Lecture during the workshop and training on epilepsy for neurologist, residents, psychiatrists, and neurosurgeons in Nigeria,

Planned activities for the ILAE-Africa region in 2020

1. Continue to conduct PET courses, venues and dates TBD. Course materials are planned to be translated into French.
2. Organize regional epilepsy awareness-raising campaigns for English- and French-speaking countries.
3. Establish the epilepsy research needs on the continent.
4. Foster South to South and North to South epilepsy-related research collaborations in the region.
5. Increase the number of countries joining the ILAE on the continent.
6. Continue production of the bi-annual news e-report, "Epilepsy News Africa".

Report by Angelina Kakooza-Mwesige

ILAE-Eastern Mediterranean Affairs



Chahnez Triki

Chair

Chahnez Charfi Triki (Tunisia)

Members

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Abdulaziz Ashkanani (Kuwait), Secretary
Reda Ouazzani Taibi (Morocco), Treasurer
Ghaieb Aljandeel (Iraq)
Fatima Abdullah (Bahrain)
Nihal El Shazly (UAE)
Boulenouar Mesraoua (Qatar)
Adel Misk (Palestine)

Management Committee Liaison

Emilio Perucca (Italy)

The ILAE-East Mediterranean Region (ILAE-EMR) was launched in 2004, and includes 16 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

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.

Executive Board Meetings

- Seven meetings via Zoom teleconference
- Two in-person meetings (Marrakesh 9th March, Istanbul December 12th-13th)

ILAE-EMR Chair's Overview

It is my privilege to share with you this report of our activity for the year 2019. This year was marked by holding the 5th EMEC, the consolidation of the activities started in 2018, and the launch of new teaching and collaboration activities. We are proud to share with you the results of these activities, and especially our vision to improve their medical and social impact on our region, and how to ensure their sustainability and development. We also want to welcome our two new chapters from Algeria and Bahrain, which will strengthen our activities, and we hope that more chapters will join us in 2020.

5th Eastern Mediterranean Epilepsy Congress (EMEC)

The EMEC is organised jointly by the International League Against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE). The Organizing Committee, chaired by Hassan Hosny (Egypt) and Chahnez Charfi Triki (Tunisia), comprised four members. The 5th EMEC Congress was held on 7-9th of March 2019 in Marrakech (Morocco). This regional congress was a great occasion to meet colleagues from several countries from the region.

The first day was devoted to the EEG and Epilepsy Course in French. The other two days included eight main sessions, with a half day for a social activity with meetings with parents and patients with epilepsy.

During this congress, YES-EMR was launched and Dr Reem Alayoubi was elected as the representative of EMR.

A chapter convention was also held during this meeting and nine chapters were present. It was an opportunity to discuss regional problems and determine the main axes to develop in the region to promote epileptology.

ILAE-Eastern Mediterranean Affairs *(continued)*



The 2nd Francophone Epilepsy and EEG course was held in Marrakech (Morocco) November 28-29, 2019, and was organized in conjunction with the 3rd Moroccan Congress of Neurophysiology and 4th session of the EEG & EMG school. The more than 2,829 participants included residents and qualified doctors from all parts of Morocco, as well as from Algeria, Tunisia, Mauritania, Senegal, Democratic Republic of Congo, Malawi, Mali, Ivory Coast, Burkina Faso, Congo, Togo, Central African Republic, Niger, Spain, France, Belgium, and Switzerland. The course included lectures and panel discussions with question-and-answer sessions. About 94% of participants recognized that the course was extremely useful for their professional improvement and their daily practice, and found the lectures and practical workshops engaging and informative.



ILAE-EMR Courses

Two regional courses were held in 2019 in both English and French, in order to reach the maximum number of members from our region. The objective of these courses is to provide epilepsy training consistent with the objectives of the ILAE; these courses correspond to the curriculum of level one and two established by the ILAE.

The EEG course in Kuwait was held on November 14-15, 2019 and had 34 participants. Ten of them were partially sponsored by ILAE-EMR. The course was linked to the Neurology conference. This course has been assessed by the participants as being complete with the latest news in epilepsy, and is very useful for daily practice.

Fellowship Program

The aim of this program is to increase the number of epileptologists in the EMR. This program is very successful for young neurologists and pediatricians in the region who find in this program an opportunity to strengthen their training in EEG and epilepsy (surgery, epilepsy in children, EEG, etc.). This year, five young epileptologists benefited from a stay of two-to-three months in international centers (Skizuoka, Japan; Rennes and Paris, France) and regional (Sfax, Tunisia). This program also encourages collaboration between different centers in the region.



ILAE-Eastern Mediterranean Affairs *(continued)*

Visiting Teacher Program

The aims of the new 2019 program are to provide mentorship and education, and improve levels of knowledge and competencies of medical doctors in the region through the visits of a volunteer professor/senior or an expert on epileptology (preferably from EMR) to an epilepsy center in EMR.

We plan to conduct all these activities in 2020 and, in order to facilitate the process for all of these regional activities, we set up internal bylaws and guidelines for all activities.

Report by Chahnez Charfi Triki, Chair of ILAE-EMR



Roberto Caraballo

Chair

Roberto Caraballo (Argentina)

Executive Board Members

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Walter M. Camargo Villarreal (Bolivia), Secretary
Mario Alonso Vanegas (Mexico), Treasurer
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Mabel Flores (El Salvador)
Lilia Maria Morales Chacon (Cuba)
Juan Carlos Perez Poveda (Colombia)

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

A new ALADE commission was elected in 2019:

Franz Chaves Sell (Costa Rica), President
Alejandro Scaramelli (Uruguay), Past-president
Patricia Braga (Uruguay), Secretary
Patricio Abad (Ecuador)
Fernando Cendes (Brazil)
Laura Guilhoto (Brazil)
Damian Consalvo (Argentina)
Alicia Bogacz (Uruguay), ex officio-IBE
Silvia Kochen (Argentina), ex officio-IBE

YES - Young Epileptologists

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

Academia Latinoamericana de Epilepsia (ALADE)

Annual Fellowships

The call for the annual fellowships of the ALADE was made for all chapters of ILAE Latin America through the website of the ILAE. Overall, 16 candidates from nine 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 three candidates that obtained the highest score were selected for the training, receiving financial support.

Itinerant Courses (“in-situ”)

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

In 2019, the ALADE itinerant courses were held in the framework of Epilepsy Weeks in Paraguay, Bolivia, and El Salvador. The ALADE courses supported a larger inclusion of subjects related to epilepsy and provided the opportunity of the presence of epileptologists.

The first ALADE course was held in Paraguay on April 11, 12, and 13, 2019. Topics were the new classification of epilepsy and seizures, semiology and video-EEG, EEG and neuroimaging in epilepsy, rational use of new AEDs, and non-pharmacological treatment alternatives, with lectures by Roberto Caraballo, Fernando Cendes, Alejandro Scaramelli, Marco T. Medina, Mario Alonso, Luis Taboada, Mario Camargo, and Franz Chaves.

The second ALADE itinerant “in-situ” course took place on June within the framework of the Epilepsy Week in Cochabamba, Bolivia in June 2019. There were 59 attendees.

The third “in-situ” course was given in the framework of the first Epilepsy Week in El Salvador on September 4 and 5, 2019. The topic of the course was, “Epilepsy in Primary Care”. It was organized by members of the Commission for Primary Care and endorsed by the ALADE. Lilia María Morales Chacón was in charge of the coordination of the course.

13th Latin American Summer School on Epilepsy – LASSE XIII

The 13th Latin American Summer School on Epilepsy was held in São Paulo from March 7 to 15, 2019, at the Hotel and Convention Center Santa Monica.

ILAE-Latin America *(continued)*

From 218 applications, 61 were selected: 31 Brazilian, nine Mexican, four Colombian, four Peruvian, three Chilean, two Argentine, two Venezuelan, two Guatemalan, two Uruguayan, one Paraguayan, and one Dominican.

On the first day, students were divided into eight groups and a tutor to each group was selected among the LASSE teachers. The group division had the following purposes: preparation of a research project related to the central topic of the School and participation case study sessions.

The School program was fully executed and followed the main theme, "Epilepsy: From Connectivity to the Connectome". An extra class, on request, was given by Dr Marina Bentivoglio on "The Meaning of Scientific Dignity in the XXI Century". On the last day of the School (March 15, 2019), groups of students presented the research projects developed under mentoring:

Group 1: Maternal epilepsy and brain fetus connectivity

Group 2: Connectivity in neurocysticercosis as a model of epileptogenesis

Group 3: Magnetic stimulation for the regulation of hippocampal ictogenesis

Group 4: Dance training modifies brain connectivity in adult patients with pharmaco-resistant temporal lobe epilepsy

Group 5: Brain connectivity changes associated with carbamazepine administration in an animal model of temporal lobe epilepsy (hippocampal sclerosis)

Group 6: Functional and effective connectivity between amygdala and the brainstem in patients with high risk of SUDEP

Group 7: Evaluation of brain connectivity changes in patients with psychogenic non-epileptic seizures exposed to cognitive behavioral therapy

Group 8: Circadian variability of resting-state networks in JME - a functional connectivity study

The discussions that followed each presentation provided an adequate assessment of participants' progress. Many of the teachers present praised the maturity of the discussions and the topicality of the research topics.

Most of the participants emphasized the excellence of

the program by introducing basic physical concepts that facilitated the understanding of the meaning of human connective anatomy, both anatomically and functionally, as well as those related to the concept of effectiveness, especially related to various epilepsy syndromes.

During the meeting of the organizing committee held on March 12, it was decided that the topic of the next edition should be, "Epilepsy Treatment: the State of Art and Challenges," scheduled to take place between February 27 and March 6, 2020.



Pediatric Epilepsy Training (PET Spanish Version)

PET courses will be available in Brazil and Colombia (from May 2020), and El Salvador (from May 2020).

A pre-congress symposium on the PET will take place in Medellin, Colombia, during the XI Latin-American Congress of Epilepsy.

Basic and Clinical Research in Epilepsy

The following research studies, started in 2018, are ongoing:

Study on Genetics in Epileptic Encephalopathies

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

Study on Cannabis in Epileptic Encephalopathies

In Argentina, a study on the use of cannabis in epileptic

encephalopathies is being conducted. Public hospitals from throughout the country participate in the study. The two-year trial has entered its second year. The study will be a model for the use of cannabis in other countries in Latin America.

Fellowship in Epilepsy in Canada

The fellowship under Dr Jorge Burneo at the Epilepsy Program, Western University, London Health Sciences Center, Canada started in 2018.

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

The first fellow has concluded the fellowship, and a call was made to the chapters and on the website of the ILAE for the next fellowship.

First Symposium: Pediatric Epilepsy and Drug Refractory Epilepsy San Salvador, El Salvador, February 24-27, 2019

On February 24-27, 2019, the first symposium on pediatric epilepsy and drug refractory epilepsy was held in San Salvador, El Salvador.

International guest speakers were Roberto Caraballo, Ángel Hernández and Jorge Vidaurre, and local speakers were Manuel Vides, Claudia Valencia, Ricardo Lungo, and René Silva.

The meeting was endorsed by the International Child Neurology Association (ICNA), Child Neurology Society (CNS), Pediatric Society of El Salvador, and the International League against Epilepsy (ILAE).

The meeting was divided into three sections:

Symposium and medical mission in San Miguel, El Salvador:

- Part A. Mini epilepsy symposium for pediatricians on 2/24/19. The symposium focused on recognition of common epilepsy syndromes and paroxysmal non epileptic events.

- Audience: Around 70 participants, mainly pediatricians. Supported by the local pediatric society of San Miguel (one of the most important and populated cities in El Salvador).
- Part B. Evaluation of clinical cases with local team on 2/25/19. Patients selected by Dr Rene Silva as Chief Pediatric Neurologist. Cases were selected due to refractoriness and potential for epilepsy surgery. Candidates for surgery were identified.

Symposium and medical mission in San Salvador (capital of the country), El Salvador:

- Part A. Symposium in pediatric epilepsy and refractory epilepsy on 2/26-28/19.
- Audience: About 120.
- The symposium started with recognition of pediatric epilepsy syndromes and other topics. The second day focused on drug refractory epilepsy and alternatives to therapy including ketogenic diet and surgical options/VNS. Conferences included data about the role of CBD in epilepsy. Clinical cases presented by local neurologists and pediatric neurologists were discussed.
- Part B. Evaluation of pediatric epilepsy cases of difficult control were evaluated by the team at the main hospital (Hospital Benjamin Bloom, the main pediatric hospital in the nation). Many of the cases were candidates for surgical intervention.

A surgical intervention was performed on 2/28 with advice from team members. Most of the surgical candidates were selected for future dates. More cases were evaluated on 2/28/19.

Special symposium for patients and families:

- Audience: About 65.
- The symposium was addressed to families and patients, in order to understand new evolving concepts in diagnosis and treatment. Panel of speakers discussed different therapeutic options. Questions from family members were answered. Families spent eight hours with panel of speakers.

ILAE-Latin America *(continued)*



Meeting of Epilepsy Centers, Santiago, Chile May 16-18, 2019

The first Meeting of Epilepsy Centers was held in Santiago, Chile, on May 16-18, 2019. The central topic of the meeting was cortical dysplasia. Speakers, among others, were Imad Najm, Juan Bulacio, (Cleveland Clinic), Patricia Braga, Daisy García, and Ingmar Blümcke (Germany) with lectures on genetics, pathology, clinical exams and surgery, as well as case discussions.



The meeting was organized following a low-cost model. It was held in a free auditorium, there were no travel costs as the speakers paid for their own tickets, accommodation was at simple hotels, and there were no expensive dinners.

Support from the ILAE (\$10,000) was used for 46 fellowships for the accommodation of LA participants. Additional to ALADE fellowships, there was support from the labs for 100 inscriptions. Forty LA centers participated with 246 attendees.

The plan is to organize this meeting yearly from now on. A special session on the ketogenic diet will be added.

Epilepsy Weeks in Paraguay, Bolivia, and El Salvador

This year, Epilepsy Weeks were organized in Paraguay, Bolivia, and El Salvador. The IBE and ALADE participated in all three epilepsy weeks.

Paraguay

Epilepsy Week in Paraguay was held from April 8 to 13, 2019. During the week, there were scientific, social, and cultural activities to increase awareness of epilepsy at the level of public health in different locations in the country.

A scientific international meeting was held for neurologists, neurosurgeons, pediatric neurologists, clinicians, general pediatricians, primary care physicians, medical students, and nurses. During the meeting, three different courses were given: Update in Epilepsy (ALADE), Primary Care in Epilepsy, and Electroencephalography. Additionally, relationships were established with the best epilepsy centers in Latin America.

Different training courses were held for patients, family members, and the general public at the most important hospitals in the country. The week closed with an artistic show, with the presence of authorities who committed to participate actively in the implementation of a national epilepsy program.

Invited speakers were Roberto Caraballo (Argentina), Dr Marco Tulio Medina (Honduras), Dr Alejandro Scaramelli (Uruguay), Dr Franz Chaves (Costa Rica), Dr Mario Alonso Vanegas (Mexico), Dr Fernando Cendes (Brazil), Dr Mario Camargo (Bolivia), Dr Alicia Bogacz (Uruguay) IBE, Laura Cristino (Uruguay), and Eduardo Medina (Uruguay).

There was active participation by the general public.



Furthermore, the ALADE course had 59 attendees (specialists), the EEG course had 35 (doctors and technicians), and the course of Primary Care in Epilepsy had 118 (family doctors, young physicians, and medical students).



A media agency was in charge of the dissemination of Epilepsy Week with information for television, radio, the press, and social media.

Bolivia

The first annual epilepsy week in Bolivia was held in 2015. In 2019, the 5th Epilepsy Week took place on July 18-19 in Cochabamba.

This latest edition of epilepsy week in Bolivia in Cochabamba was organized according to the different lines of the project: education of patients and families, reduction of discrimination and stigma in the society, training of primary health-care workers, support from the authorities, and research.

In the framework of education and awareness of the population, including people with epilepsy and their families, there were training courses with educational material in two different cities of the country.

To reduce the stigma, discrimination, and social exclusion of people with epilepsy, a country-wide advertising campaign was held, including a press conference, media tours, distribution of educational material, and the video entitled, "What does it mean to live with epilepsy?".

For health care workers in primary care and medical students, a course was held to improve skills in the diagnosis and management of epilepsy at three different locations in the country.

The need for the creation of epilepsy centers, and the control of quality and prices of antiepileptic drugs was emphasized in a meeting with the authorities. These projects will be supported by PAHO.

Finally, a symposium was held for epilepsy specialists (neurologists, child neurologists, educational therapists, psychiatrists, and EEG technicians) with case discussions and update lectures.



El Salvador

The first Epilepsy Week in El Salvador took place from September 1 to 7, 2019 with a large series of academic and cultural events.

Activities began on September 1 with the first 5KM run for epilepsy, a unique event that attracted more than 150 participants, including doctors, paramedics, patients, and family members --both professional and amateur runners with the goal of raising awareness of epilepsy in the general public.

On September 2 and 3, visits were made to universities and hospitals to give update lectures on epilepsy and its management, and discussion of clinical cases with participation of medical students and residents of internal medicine and neurology. Attendance was over 200 for some of the lectures.

More than 30 specialists participated in the symposium for neurologists, discussing the situation of epilepsy in Latin America and the classification of epilepsy, among other topics.

On September 6, a press conference was held for the media to publicize the national and regional problems related to epilepsy and strategies to address these problems. Simultaneously, at the Tin Marín Children's Museum, playful activities were presented that allowed epilepsy specialists to talk to children about the disease, and what to do when someone has a seizure. The play, "Carlitos and Epilepsy," with a message of non-stigmatization of the disease, was presented to more than 300 children in just one morning.

The courses of Epilepsy in Primary Care and Electroencephalography for Technicians had attendees from across the country: Physicians and family medicine, internal medicine, and neurology residents attended on September 4, and EEG technicians on September 5.

The week concluded with the International Symposium on Epilepsy, which took place on September 6 and 7 and included activities for medical and paramedical personnel, and patients and their families, while a simultaneous EEG meeting was held for technicians.



Program on Epilepsy Education

On 16, 23, and 30 August, the Program on Epilepsy Education was carried out and addressed to teachers in the three main districts of the Province of Entre Ríos, Argentina — Paraná, Concordia, and Gualeguaychú. The Program was endorsed by the government of the province and the Board of Education of Entre Ríos. The Board of Education handed out a certification and conferred credits for participating in the Program. The Program consisted of lectures on epilepsy in general and neuropsychological aspects of epilepsy, and videos of epileptic seizures in school-age children were shown, as well as a short movie about a pupil with epilepsy during a school camp. Before and after the Program, a questionnaire was administered to evaluate knowledge, attitudes, and practices. For the course, a book entitled, "Epilepsy in the School" was written. In the districts of Paraná, Concordia and Gualeguaychú, 1,600, 1,500, and

1,100 teachers participated, respectively. A PDF version of the book is available on the official website of the Board of Education for all the teachers in the province, as well as on the web site of the ILAE: (<https://www.ilae.org/files/dmfile/Epilepsy-in-the-School---Caraballo-2019.pdf>).

Latin American Epilepsy Congress (LAEC 2020)

The XI Latin-American Epilepsy Congress will be held in Medellín, Colombia, in May 2020. A comprehensive program is being prepared that will include clinical, educational, surgical, and research aspects related to epilepsy in children and adults.

In addition, the usual symposia for the general public with social and educational items are being organized.

Well-known speakers from both inside and outside the region have been invited.

Telemedicine

In Salta, Argentina, a symposium on telemedicine and epilepsy was held on September 6, 2019. The meeting was a success; around 300 doctors participated and, through the telemedicine network, doctors from throughout the country were connected during the entire meeting. Dr Sam Wiebe, Roberto Caraballo, Damian Consalvo from the Argentine League against Epilepsy, and several other leading epileptologists as well as local authorities, discussed the most prevalent epileptic syndromes and topics related to the field. Initially, a model of telehealth and epilepsy was presented.

A video was prepared for the meeting to show how the program is working. The video showed the reality of children with epilepsy and their families that live in remote areas without access to care, and how they benefit from telemedicine, mainly regarding care aspects.

Regarding educational activities, currently a program to educate doctors, nurses, and others who work in primary health care is being developed using telemedicine including talks, books, and questionnaires before and after the program, to demonstrate its impact. The program will be implemented in all the Argentine provinces.



Several countries in the region (Brazil, Colombia, México) are already working with telemedicine.

Sebastian Fortini (Argentina) was assigned to be coordinator of the Commission for Telemedicine in Latin America.

Young Epileptologists – YES

Johann Sebastián Ortiz de la Rosa and Viktor Navarrete-Modesto are coordinating the key activities of the YES in the region.

The following activities were developed in 2019:

- The Spanish (Sebastián Ortiz, Colombia) and Portuguese (Patricia Saletti, Brazil) ILAE twitter accounts were launched.
- The ILAE Facebook content was translated into Spanish and Portuguese (Patricia Saletti for Portuguese translation and Helena Franco for Spanish translation).
- ILAE infographics were translated into Spanish and Portuguese.
- YES participated in the Epilepsy Awareness Day in Colombia at the Hospital Militar in Bogotá, Colombia (Paula Martínez Micolta, Juliana Vargas and Manuela Ochoa).
- Elections were held to choose country representatives for YES in Latin America (México, Guatemala, Dominican Republic, Honduras, El Salvador,

Colombia, Venezuela, Ecuador, Chile, Argentina, Brazil, Paraguay, and Uruguay).

- The Latin-American YES group was divided into four internal divisions: Education (Diego Jiménez, Ecuador), Research (Víctor Navarrete, México), Communication (Claudia Cominotti, Argentina), and Advocacy (Manuela Ochoa, Colombia).
- www.epilepsydiagnosis.org was translated into Spanish (Alejandra Genel from México, Ana Suller from Spain, Carolina Vargas and Sebastián Ortiz from Colombia).
- YES members assisted in case development for the ILAE curriculum (Manuela Ochoa – TLE and Sebastián Ortiz - CAE).
- A Latin American newsletter will be issued (Claudia Cominotti – Argentina).
- A Latin American database for resources and courses was developed (Diego Jiménez – Ecuador and Claudia Cominotti – Argentina).
- There was an official launch of YES country liaisons in the Dominican Republic, Colombia, and México.

Members of the YES are currently participating in the organizing committee of the Latin-American Epilepsy Congress. Additionally, a YES committee was created to plan and develop the YES activities during the the 2020 Latin-American congress.

This committee was divided into three working groups as follows:

- Advertising and promoting our YES events
- Conference planning (submitting proposals and arrangements)
- Local people to establish the networking event and other activities

Different activities have been organized to stimulate young epileptologists to attend the congress and to raise money for the YES. The money that is raised will be used to have one fellowship to the LASSE (Latin American Summer School on Epilepsy).

Joint activities with local organizations, IBE, and PAHO *Strategy and Plan of Action on Epilepsia of Latin America and the Caribbean 2021-2031*

On Wednesday, June 6, a second video conference was held with Claudina Cayetano (Chief Mental Health PAHO), Jorge Rodríguez (PAHO Consultant), Roberto Caraballo (ILAE Latin America), Carlos Acevedo (Collaborating Center PAHO-Chile), Marco Tulio Medina (Collaborating Center PAHO-Honduras) and Tomás Mesa (IBE Latin America) to organize and plan the next Strategy and Plan of Action on Epilepsia of Latin America and the Caribbean 2021-2031

This future Strategic Plan will be the guide for the development of future policies and actions in our region, in line with the activities that are being developed at the central level of WHO.

Devora Kestel (WHO) will support this re-accreditation management of the Strategic Plan.

ILAE-LA Website

Claudia Cominotti, a member of the YES LA, is currently responsible for the ILAE LA website. On the website, all regional and national meetings, congresses, and others scientific activities are announced (<https://www.ilae.org/translated-content/spanish>). Visits from Spanish speaking individuals are increasing.

Report by Roberto Caraballo, Chair, ILAE-Latin America

ILAE-North America Region



Nathalie Jetté

Chair

Nathalie Jetté, MD MSc FRCPC

Members

Sheryl Haut (USA), Past-chair

Mary Lou Smith (Canada), Secretary

Karen Parko (USA), Treasurer

Amy Brooks-Kayal (USA)

Jorge Burneo (Canada)

Dave Clarke (Caribbean)

Jaideep Kapur (USA)

Ex-Officio

Amza Ali (Jamaica), President, Epilepsy Society of the Caribbean

William Gaillard (USA), President, American Epilepsy Society

Dang Nguyen (Canada), President, Canadian League Against Epilepsy

Taylor Abel (USA), YES Representative

Eileen Murray (USA), Executive Director, American Epilepsy Society

Management Committee Liaison

Samuel Wiebe (Canada)

Aims/Goals of the Commission

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. Contribute to the development of our future epilepsy leaders;

2. Contribute to the advancement of knowledge by organizing a regional congress;
3. Contribute to the education of trainees and early career clinicians and scientists by supporting activities such as courses in clinical epilepsy, the neuropsychology of epilepsy, basic science mechanisms, and leadership development;
4. 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, and shortening placebo exposure through time to event designs;
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.

Commission Activities and Accomplishments:

Leadership Development Course

The 4th ILAE Leadership Development Program was held June 21-22 in Bangkok, Thailand in conjunction with the 33rd International Epilepsy Congress. As indicated by participant evaluations, the program was a success. Similar to previous years, the course took place over one-and-a-half days, and included a networking lunch with ILAE Executives and other invited faculty and leaders. The 2019 program included 29 participants and incorporated small curricular modifications from previous years, including the addition of a session focused on building and leading collaborative studies. Since 2015, over 100 individuals have been trained.

San Servolo Epilepsy Course

The ILAE-NA region provided funding for an attendee from Jamaica to attend the San Servolo course. The funding was targeted toward the Caribbean in order to support our efforts to increase knowledge and improve epilepsy care in that region.

Global Health Task Force

This was the second year of the Global Health Task Force which was created with the intent of expanding the scope of the Intercommission Educational Outreach. The mission of the task force is to advance epilepsy education and care internationally. The task force has 15 members with representation from the three chapters in ILAE-NA, as well as representation from the ILAE/IBE Global Outreach Task Force.

In 2019, the task force held nine conference calls/meetings. Two reports were also completed. The first was a review on global health and epilepsy: Spiciarich MC, von Gaudecker JR, Jurasek L, Clarke DF, Burneo J, Vidaurre J. Global health and epilepsy: Update and future directions. *Current Neurology and Neuroscience Reports*. 2019;19(6):30. doi: 10.1007/s11910-019-0947-6.

The second report was the construction and opening of an online repository housed on the ILAE website (<https://www.ilae.org/regions-and-countries/regions/ilae-north-america/global-health-database>). The goal and mission of the repository is to improve the care of persons with epilepsy globally by increasing collaboration, reducing redundancy, directing resources, promoting advocacy, and identifying volunteers, as well as targeting potential funding for future global health projects. The repository was launched at the 2019 American Epilepsy Society Meeting. The plan is to pilot the response and usefulness of the website within ILAE-NA, and then to include all ILAE regions.

A Center-to-Center Program to improve the care of patients with epilepsy in the Caribbean: A pilot application for Trinidad and Tobago.

The Center-to-Center Program is an initiative of the ILAE-NA region to provide support to underserved Caribbean areas to improve the care of patients with epilepsy. In this first pilot application, the University of Montreal Health Center (Mentor Center) was matched with the Eric Williams Medical Sciences Complex in Trinidad (Mentee Center).

For the first year of this pilot project:

- a. An assessment of gaps/needs was conducted;
- b. A series of 14 webinars on epilepsy in both English and French (CME-accredited) were created, to be given monthly between October 15, 2019 and February 16, 2020;
- c. A three-day epilepsy course was held at the Eric Williams Medical Sciences Complex from November 18-20, 2019 (morning lectures, afternoon clinics and an evening symposium).

Regulatory Affairs Task Force

This year was focused on two topics. The first was the issue of infant epilepsy. The task force members developed and wrote a novel design which was published as an ILAE report (Auvin S, French J, Dlugos D, Knupp KG, Perucca E, Arzimanoglou A, Whalen E, Shellhaas RA. Novel study design to assess the efficacy and tolerability of antiseizure medications for focal-onset seizures in infants and young children: A consensus document from the regulatory task force and the pediatric commission of the International League against Epilepsy (ILAE), in collaboration with the Pediatric Epilepsy Research Consortium (PERC). *Epilepsia Open*. 2019 Sep4;4(4):537-543). The design was also used as a post-hoc analysis of fenfluramine that was presented at the Annual Meeting of the American Epilepsy Society, which demonstrated that the design would have been successful using real data. The second issue undertaken by the Regulatory Affairs Task Force members was to respond to the draft EMA guidelines that are under review at the present time.

Pan American Health Organization (PAHO) Task Force

The PAHO Task Force emerged out of a meeting held in Trinidad in March 2018 hosted by PAHO and to which Executive Members of the ILAE, members of its Commission on North America, members of the Latin American Commission, and members of the Epilepsy Society of the Caribbean (ESC) were invited. Having

ILAE-North America *(continued)*

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 Task Force was formed.

Several goals were identified for this collaboration, including increasing the availability of anti-seizure medications and improving driving regulations in the Caribbean. Regarding the first priority, Dr Morris Scantlebury drafted a document that calls for a wider range of anti-seizure medicines for Barbados, which has been submitted to Dr Claudina Cayetano of PAHO. This template will then be used to produce similar documents for the other individual islands, as needs differ across the region.

The most pressing issue of widest Caribbean relevance is that of inadequate driving regulations. In recognition of this, a Demonstration Project was launched by ILAE North America to address restrictive driving regulations in the Caribbean, beginning with Antigua. Relevant stakeholders were identified, and progress has been made. During the latter part of 2019, the concept emerged of hosting a symposium on "Driving in the Caribbean," to be held in June 2020. Key stakeholders including members of the government, medical community, legal profession and the public will work on relevant projects and will present their work at this symposium.

Recommendations for Future Work

We will be hosting the first ILAE-NA Regional Congress to be held in Toronto, Canada on September 25-27, 2020. We are planning the next Leadership Development course in conjunction with this ILAE-NA regional congress.

We will continue to support educational opportunities for young professionals in epilepsy by providing a variety of bursaries, including bursaries to attend the first ILAE-NA congress.

The Driving in the Caribbean symposium of the PAHO Task Force to be held in June 2020 will provide a hard timeline to ensure each subproject aimed at developing appropriate driving regulations 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. Finally, reinforcing and building relationships with PAHO will be an ongoing strategic objective of this ILAE task force.

The Center-to-Center Program to "Improve the Care of Patients with Epilepsy in the Caribbean" will pursue its work with phase two of the project in the year 2020, and will work toward extending this program to other Caribbean Islands such as Guadeloupe.

The next meeting of the Regulatory Affairs Task Force will be with EMA in Geneva at the European Congress in 2020.

The Global Health Task Force would like to work with the ILAE/IBE Global Outreach Task Force to involve all ILAE regions in creating and sustaining an international global health directory that will serve as the "go-to" place for anyone around the world working in global health and epilepsy.

Report by Nathalie Jetté, MD MSc FRCPC, and Mary Lou Smith, PhD

Education Council



Ingmar Blümcke



Wei-Ping Liao

The Education Council came into existence in September 2019, replacing the Epilepsy Education Task Force (EpiED).

Epilepsy Education Task Force

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)

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)

Leonor Cabral-Lim (Philippines)

Nicola Maggio (Israel)

Ivan Rektor (Czech Republic)

Jo Wilmshurst (South Africa)

Sarah Wilson (Australia)

Elza Marcia Yacubian (Brazil)

Christoph Schöne-Bake (Germany)

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

Achievements in 2019

EpiEd published 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). The paper is made available open access and can be also downloaded from the ILAE website.

We have developed the ILAE Academy IT-platform based on a Totara Learning Management System for structured learning programs in epileptology. The ILAE Academy will host a series of 15 case-based eLearning modules of the most common epilepsies (Level 1 – high probability/low complexity), 50 ebrain modules previously developed by JNC and revised by EpiEd, VIREPA-EEG courses (Level 2), and a new tutorless and self-paced MRI teaching platform (Level 1). This learning portfolio is currently in development and β -testing, and will be made fully available for our constituency in 2020.

The ILAE congress in Bangkok offered the first series of full- and half-day teaching sessions addressing important competencies in epileptology.

Future Plans

The EpiEd Task Force terminated and was replaced by the ILAE Education Council, effective September 2019. However, the mission of the Education Council will remain the same. In 2020, we will officially launch the ILAE Academy, offering a certificate-based learning program for Level 1 and Level 2, including self-paced eLearning modules,

Education Council *(continued)*

face-to-face courses, and teaching sessions at congresses and workshops. Each teaching activity will be mapped to learning objectives as specified by the curriculum. Another goal is to make our courses available in other languages, i.e., Spanish, and adapting the content to specific socio-economic background of the target audience.

Education Council members

Ingmar Blümcke (Germany), Chair
Alexis Arzimanoglou (France)
Sandor Beniczky (Denmark)
Fernando Cendes (Brazil)
Helen Cross (UK)
Jean Gotman (Canada)
Nicola Maggio (Israel)
Man Mohan Mehndiratta (India)
Christoph Schöne-Bake (Germany)
Gagandeep Singh (India)
Chahnez Triki (Tunisia)
Sam Wiebe (Canada)
Jo Wilmshurst (South Africa)
Sarah Wilson (Australia)
Elza Marcia Yacubian (Brazil)

Report by Ingmar Blümcke

Publication Council



Jean Gotman

The Publication Council came into existence in September 2019. The Publication Task Force (TF) concluded its existence at that time.

Members of the Publication TF who will remain on the Publication Council

Jean Gotman, Chair
Alexis Arzimanoglou (France), Sándor Beniczky (Denmark), Editors-in-Chief, *Epileptic Disorders*
Aristea Galanopoulou (USA), Dong Zhou (China), Editors-in-Chief, *Epilepsia Open*
Astrid Nehlig (France), Michael Sperling (USA), Editors-in-Chief, *Epilepsia*
Nicola Maggio (Israel), Editor-in-Chief, ILAE Wikipedia Project
Emilio Perucca (Italy)
Ed Bertram (USA)

New members of the Publication Council

Emmanuel Sanya (Nigeria), representing Africa
Marco Medina (Honduras), representing Latin America
Salah Baz (Saudi Arabia), representing the East Mediterranean
Ingmar Blümcke (Germany), representing the Education Council

Chair

Jean Gotman (Canada)

The Publication Council now has representation covering all ILAE regions. Members have various terms, so that many will continue past the change of the ILAE Executive Council in 2021. Editors-in-Chief are no longer members of the ILAE Executive Committee. The Chair is a non-voting member of the Executive Council.

Activities of the Publication Council

The reports of ILAE organizational entities that are considered for publication are first reviewed by the

Publication Council, which makes a recommendation to the Executive Committee (EC) regarding the following points:

- Whether the report is of sufficient importance and quality to be published in an ILAE journal (The Publication Council does NOT review the report.)
- The journal to which the report is to be submitted.

The EC makes the final decision. A two-page Executive Summary of the report is published in *Epilepsia* independently of where the report is published. An Executive Summary has only one reference, to the original paper.

Epilepsia

- The journal is gaining a reputation for being tougher; rejection rates continue an upward trend
- Rate of submission remains constant, with a small increase in original research
- Continued growth in basic science and pediatrics submissions
- The number of downloads is impressive; they have tripled in the past decade
- The impact factor increased to 5.56 in July 2019, from 5.23 in July 2018
- The possibility of creating podcasts was discussed but no conclusion was reached.

Epilepsia Open

- Steady increase in number of articles published
- Upward trends continue for downloads/unique visitors
- Increase in direct submissions vs transfers continues
- Revenue is increasing compared to this time in 2018, but relatively slowly.

Epileptic Disorders

- Total submissions are slightly higher than last year

Publication Council *(continued)*

- The Epilepsy Education TF paper on the curriculum roadmap was published in April
- A series of articles related to the curriculum will be published starting in the fall (two have been published, eight are in process)
- Improvements have been made to the video search functions on the journal website
- The Impact Factor increased to 2.05 in July 2019, from 1.50 in July 2018.

Wikipedia Project

- Engagement with the YES group to recruit new writers, particularly through social media
- Training of new writers using open-access resources from the Wikipedia Educational Foundation
- Workshop in Bangkok on writing for Wikipedia, given by Amin Azzam, MD – a Professor of Psychiatry at UCSF and a Wikipedian – was attended by 30 people. This workshop will be repeated in Geneva.
- Ten entries are in process of being uploaded to Wikipedia, after a thorough review by a specialist in the field; five are currently being written by people who attended the Bangkok workshop
- Overall, the writing of Wikipedia entries has proven a lot more complex than originally envisioned.

Contract with Wiley

- The contract with Wiley ends in December 2021
- We hope to have a new contract in place by the end of 2020
- Initial discussions with Wiley indicate that the big open-access movement is creating much uncertainty in publishing. Discussions will start in earnest in June
- We have agreed to a six-month trial of advertising on the first pages of PDF articles downloaded from *Epilepsia*, to compensate for lost advertising revenue in print.

Cost of digital subscriptions

An effort was made to reduce the cost of journal subscriptions in countries with limited means. The following change is effective in February 2020:

- Current (2019)
 - \$0 for low income countries (31)
 - \$35 for lower middle (47) and higher middle (60) income countries
 - \$45 for high income (79) countries
- New (February 2020)
 - \$0 for low-**and lower-middle**-income countries
 - \$35 for higher middle-income countries
 - \$45 (*Epilepsia*) and \$60 (*Epileptic Disorders*) for high-income countries
- Lower-middle-income countries include large countries such as Egypt, India, Indonesia, Nigeria, Pakistan, and the Philippines
- An advertising campaign will be undertaken to make these new rates known.

Translations

An effort was made to encourage chapters to translate the main ILAE documents to make them easily accessible to a large community.

- The Definition of Epilepsy (2015) has been translated to ten languages
- The Seizure Classification (2017) has been translated to 13 languages
- The Classification of the Epilepsies (2017) has been translated to 11 languages
- The 3 documents have been translated to Arabic, French, Italian, Japanese, Portuguese (x2), and Spanish.

Report by Jean Gotman

Budget Review Task Force



Lynette Sadleir

Chairs

Lynette Sadleir (New Zealand)

Members

Michel Baulac (France)
Raidah Al-Baradie (Saudi Arabia)
Amza Ali (Jamaica)
Andrew Cole (USA)
Alejandro De Marinis (Chile)
Richard Idro (Uganda)
Kristina Malmgren (Sweden)
Uma Menon (USA)
Gagandeep Singh (India)
Nigel Tan (Singapore)

MC Liaison

Helen Cross (UK)

Aims/Goals of the Commission

To provide an independent assessment of the ILAE Commission and Task Force annual budgets.

Commission Activities and Accomplishments

The Budget Review Committee provided scores for 97 different activities from the ILAE Commissions and Task force 2020 budgets. The activities were scored based on:

1. Contribution to the ILAE Strategic Plan;
2. Methodology;
3. Synergy with other commissions or regions;
4. Timelines – Milestones;
5. Deliverables;
6. Financial Plan.

Recommendations for Future Work

Not available.

Report by Lynette Sadleir

Elections Commission



Emilio Perucca

Chairs

Emilio Perucca (Italy)

Members

Nico Moshé (USA), Past-chair

Birinus Adikaibe (Nigeria)

Jackie French (USA)

Hassan Hosny (Egypt)

Makiko Osawa (Japan)

Peter Wolf (Denmark)

Elza Márcia Yacubian (Brazil)

Preparations for the election of officers for the next term started in October 2019. Individuals eligible to run for the position of President were contacted and asked whether they were willing to be candidates for the presidential election. Three individuals (Ed Bertram, Helen Cross, and Marco Medina) responded affirmatively. Their Curriculum Vitae and Election Statements were posted on the League's website. The timeline for the election as scheduled at the time of submission of the present report is as follows:

- 17 February 2020: Starting date for the election of the President (to be completed by April 10, 2020, unless a runoff is needed);
- 20 July 2020: Starting date for the election of Management Committee members (to be completed by August 14, 2020);
- 21 September 2020: Starting date for the election of Regional Chairs (to be completed by October 16, 2020, unless a runoff is needed);
- 25 January 2021: Starting date for the election of Regional Commission members (to be completed by February 19, 2021)

The Committee wishes to thank Mr. Gus Egan for his very efficient assistance during the election process.

Report by Emilio Perucca, Election Commission Chair

Global Outreach Task Force (GOTF)



Shichuo Li



Mary Secco

Co-chairs

Shichuo Li (China)
Mary Secco (Canada)

Members

Alla Guekht (Russia), Past-chair
Seinn Mya Aye (Myanmar)
Martin Brodie (Scotland), IBE President
Leonor Cabral Lim (Philippines)
Lilian Cuadra Olmos (Chile)
Tarun Dua (Switzerland), WHO
Gardiner Lapham (USA)
Jacob Mugumbate (Zimbabwe)
Emilio Perucca (Italy)
Pravina Shah (India)
Sam Wiebe (Canada), ILAE President

WHO EB144 Meeting – February 2019

Through the efforts of the GOTF, the Russian delegation raised a proposal that epilepsy be further discussed at the May 2019 World Health Assembly. Specifically, “to seek a new report on the implementation of Resolution WHA68.20 at the 74th WHA in 2021; to seek development of a ‘Global Action Plan on Epilepsy’ to inspire the creation of a broader public-private coalition for further innovative programs and activities, consistent with the objectives of the Resolution.” This proposal was supported by China, Jamaica, Chile, and Indonesia. The Executive Board members decided that epilepsy would be further discussed at the EB146 meeting in February, in 2020.

Official Epilepsy Side Event at the World Health Assembly – May 2019

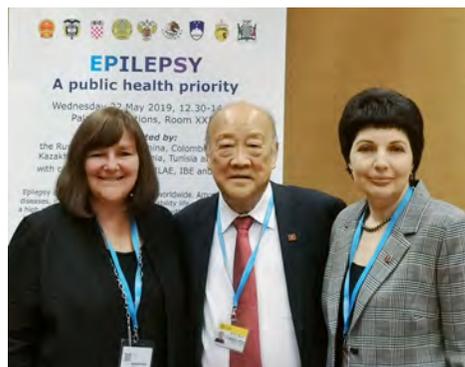
Getting epilepsy on the formal agenda of the WHA was not an easy task. It happened because of the collaborative response led by Alla Guekht from the Russian Federation. The event was co-sponsored by nine Member States: the Russian Federation (the primary applicant), China, Colombia, Croatia, Kazakhstan, Mexico, Slovenia, Tunisia, and Zambia.

The objectives of this side event were:

- To review the scope and magnitude of the burden of epilepsy globally and to identify the underlying systemic issues affecting access to Universal Health Care (UHC) and essential medicines.
- To pre-launch the Global Epilepsy Report, and to discuss the key strategies for strengthening leadership and governance in epilepsy, facilitating comprehensive health care response, eradication of stigma, extending prevention, and research in epilepsy.
- To learn from the experiences of several Member States that have implemented demonstration projects to improve epilepsy care and access to anti-seizure medicines.
- To strengthen Member State commitment to develop a plan of action to address epilepsy as a public health priority.

At the May 22 official epilepsy side event there were 120 attendees, representing 39 countries and all regions of the world. This side event brought together policy makers, NGOs, patients, health care leaders and Member States to develop next steps for implementation of WHA68.20. Ministries of Health from different WHO regions talked about the underlying systemic issues that affect access to UHC and essential medicines for persons with epilepsy in their regions. The speakers addressed the barriers, recommended solutions to strengthen systems and practices, and issued a call for urgent action by all key stakeholders at

the national and international levels.



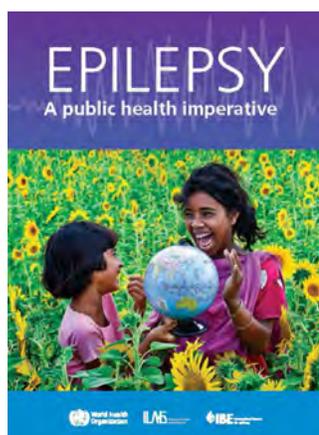
Mary Secco, Shichuo Li, and Alla Guekht at the WHA Official Side Event on Epilepsy.

Global Outreach Task Force *(continued)*

The event attendees came from the following countries: Algeria, Bhutan, Botswana, Canada, China, Colombia, Eritrea, Ethiopia, Germany, Ghana, Guyana, Honduras, Iraq, Kazakhstan, Kuwait, Lebanon, Libya, Madagascar, Malta, Mexico, Netherlands, Oman, Palestine, Philippines, Russia, Saudi Arabia, Slovenia, Solomon Islands, South Africa, Sri Lanka, Sudan, Switzerland, Thailand, Tunisia, United Kingdom, United States, Yemen, and Zambia. There were representatives from several NGOs, including the World Federation of Neurological Surgeons, International Federation of Medical Students, Health Action International, Ecodev-Sud, People's Health Movement, International Pharmaceutical Student's Federation, Global Health Constituency, UCL School of Pharmacy, IBE, ILAE, and the WHO Regional Offices and WHO Headquarters. The 90-minute program included formal presentations from WHO leadership, the Russian Federation, China, Croatia, Tunisia, Kazakhstan, Zambia, and Canada.

WHO-ILAE-IBE Launch of the Global Report on Epilepsy – June 2019

Epilepsy: A public health imperative is the first global report on epilepsy, and an important milestone in translating the World Health Assembly resolution (WHA68.20) on the global burden of epilepsy into action. The report highlights epilepsy as a public health priority, and strongly encourages investment in reducing its burden.



The report is a global call for action to combat stigma, change legislation, and address the gaps in epilepsy knowledge, care, and access to safe and affordable anti-seizure medicines around the world.

The development of the report was the major priority of the Global Outreach Task Force for the past two-plus years. The report includes contributions from 59 writers and 38 expert reviewers plus survey responses from ILAE and IBE chapters representing 101 countries.

A complete list of all the contributors can be found in the acknowledgment pages of the final report. We wish to offer the Project Coordination and Editing Team members a special thank you, to acknowledge their dedication and time commitment: Tarun Dua (WHO), Meredith Fendt-Newlin (WHO), Alla Guekht (ILAE), Nathalie Jetté (ILAE), Mary Secco (IBE), and Hiral Shah (WHO).

Delegates at the 33rd International Epilepsy Congress were given a copy of the 12-page executive summary when they registered. Copies of the 160-page full report were distributed at the IBE AGM and ILAE Chapter Convention. The executive summary has been translated into the six official WHO languages – Arabic, Chinese, English, French, Russian and Spanish – and it is available on the WHO, ILAE, and IBE websites.

The report was officially launched in Bangkok at the 33rd International Epilepsy Congress on Monday, June 24th. Regional launches of the report followed at the African Epilepsy Congress in Entebbe, Uganda and at the AES meeting in Baltimore. The report was also distributed at the WHO Global Meeting to Accelerate Progress on NCDs and Mental Health in Oman.

The full report was translated into the Chinese language and published in China. This was accomplished by Shichuo Li, with the support of the WHO Representative's Office in China.



Calling for a Global Plan of Action for Epilepsy – WHO EB146

The burden of epilepsy is too often neglected in public health agendas. In all parts of the world, people with epilepsy are the target of discrimination and human rights violations. Urgent action is needed to scale up efforts to address the highly treatable nature of epilepsy, the many outstanding gaps in its prevention and treatment, and the potential for scaling up implementation of proven cost-effective measure to reduce the epilepsy treatment gap.

Sustained and coordinated action to prioritize epilepsy in public health agendas is required at the global, regional, and national levels. Proposed by the Russian Federation and co-sponsored by China, the EB is requested to finalize the WHO Technical Policy Brief on Epilepsy, including a set of essential immediate actions to strengthen country actions against epilepsy.

At the end of the 2019 calendar year, the Russian Federation (many thanks to Alla Guekht) had officially requested the support for the Global Acton Plan, and extensive consultations between the Russian Mission in Geneva, WHO secretariat and a number of Member States was ongoing. The proposal had been officially supported by People's Republic of China, Georgia, USA, Chile, Italy, Switzerland, Honduras, Austria, Greece, Zambia, Malawi, and Zimbabwe. We will have more to report in our 2020 Annual Report at the Executive Board meeting in February 2020.

Report by Shichuo Li and Mary Secco

Guidelines Task Force



Nathalie Jetté



Francesco Brigo

Commission Co-chairs

Nathalie Jetté, MD MSc FRCPC (USA)

Francesco Brigo, MD (Italy)

Members

Sanjaya Fernando (Sri Lanka)

Jackie French (USA)

Lara Jehi (USA)

Martin Kirkpatrick (UK)

Eva Kumlien (Sweden)

Katia Lin (Brazil)

Driving Sub-Task Force Core Advisory Group

Nathalie Jette (USA), Co-chair

Alejandro De Marinis (Chile), Co-chair

Amza Ali (Jamaica), Secretary

Ettore Beghi (Italy)

Tarun Dua (WHO)

Alla Guekht (Russia)

Seung Bong Hong (Korea)

Colin Josephson (Canada)

Makiko Osawa (Japan)

Mary Secco (Canada)

Michael Sperling (USA)

Eugen Trinkka (Austria)

Manjari Tripathi (India)

Yuping Wang (China)

Sam Wiebe (Canada)

Anthony Zimba (Zambia)

MC Liaison

Samuel Wiebe (Canada)

Aims/Goals of the Commission

The task force's goals are aligned with those of the ILAE, namely to:

- Serve all health professionals as a premier international resource for current and emerging knowledge on epilepsy prevention, diagnosis, treatment, and research;

- Serve as an international information resource and leader.

The overall aim of our task force is to provide guidance and support regarding epilepsy clinical practice guideline (CPG) development and implementation in order to improve care and outcomes in persons living with epilepsy.

More specifically, the purpose of our task force is to:

1. Develop a CPG development toolkit webinar;
2. Create a webpage on the ILAE website for this TF with links to existing epilepsy guidelines;
3. Update the list of epilepsy guidelines annually and upload them to the ILAE 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";
7. Develop international driving standards.

Commission Activities and Accomplishments

- We reviewed and approved several CPG proposals submitted to our task force, and provided methodological comments and suggestions on how to improve the development of these CPGs.
- We created a database of all CPG proposals received so far, which we will update regularly.
- We developed a system to assess and rate CPG proposals in order to guide their prioritization. This will ensure that the allocation of financial and human resources to groups developing CPGs is explicit and transparent.
- We updated and refined the specific framework for CPG development with a toolkit aimed at facilitating the creation of high-quality epilepsy-specific guidelines (previous version was published as: [Developing clinical practice guidelines for epilepsy: A report from the ILAE Epilepsy Guidelines Working Group](#). *Epilepsia*.)

Guidelines Task Force *(continued)*

2015;56(12):1859-69.). In addition, we have established a joint collaboration with the Cochrane Epilepsy Group (Coordinating Editor: Tony Marson, University of Liverpool) in order to facilitate the search of available high-quality and updated systematic reviews applicable to the objective and scopes of the CPGs.

- We are currently developing a policy for collaboration and endorsement with other groups (e.g. European Academy of Neurology, American Epilepsy Society). The agreement with the European Academy of Neurology was formalized at the EAN Congress in Oslo (Prof Eugen Trinka).
- We developed a CPG development toolkit webinar.
- We ran the literature search to identify recent epilepsy related CPGs published in the past year (update to be finalized 2020).
- A driving task force was also created to develop recommendations that will support worldwide efforts to facilitate the implementation of fair and equitable driving regulations for people with epilepsy (PWE). A systematic review of driving outcomes and risks is in process and is expected to be completed in early summer 2020. An inventory of driving standards is in progress and will be available on the ILAE website. A driving risk assessment tool will be developed based on the systematic review, along with standards.

webinar to all task force and commission members.

- We will create a webpage on the ILAE website with links to existing epilepsy CPGs.
- We will update the systematic review on existing CPGs in epilepsy (previous versions published as: [The current state of epilepsy guidelines: A systematic review](#). *Epilepsia*. 2016;57(1):13-23.).
- We will finalize and formalize a policy for collaboration with the American Epilepsy Society and other relevant organizations.
- We will write an educational paper with the aim of explaining what CPGs are, and how to develop and implement them (expected to be completed spring/summer 2020).
- We will submit a proposal for a one-day CPG development workshop at the next International Epilepsy Congress.
- The following are expected to be completed in 2020 for the driving task force: (1) inventory of driving standards; (2) define gaps in the area of driving research/policy; (3) complete a systematic review of driving outcomes and risk; (4) develop a driving risk assessment tool; and (5) begin the development of driving standards expected to be completed in 2021.

Report by Nathalie Jetté, MD MSc FRCPC and Francesco Brigo, MD

Future Plans

- We will continue to review CPG proposals submitted by commission/task force members who are seeking ILAE endorsement and methodological expertise.
- We will disseminate the updated and revised CPG workflow template and process map to all task force and commission members.
- We will disseminate the prioritization system for CPG proposals to all task force and commission members.
- We will disseminate the CPG development toolkit

Joint ILAE-IFCN EEG Task Force on EEG Databases



Sándor Beniczky

Chair

Sándor Beniczky (Denmark)

ILAE

Jean Gotman (Canada), EC Liaison

Ingmar Blümcke (Germany)

Don Schomer (USA)

William Tatum (USA)

Sam Wiebe (Canada)

Elza Márcia 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

Aims/Goals of the Commission

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: 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.

Commission Activities and Accomplishments

The Joint Task Force developed a detailed proposal for the development of the database, including the technical details

and the costs. The proposal has been approved by the ILAE, including the budget for 2019. IFCN was supposed to cover 50% of the costs, as agreed at the meeting in New Orleans in December 2018, where IFCN was represented by its treasurer. However, the Executive Committee of the IFCN decided in February 2019 that the costs of the bridging solution were too high, and they opted to wait until the development of the final functionality. This will take 18-24 months, but the costs of running the final functionality will be much lower, because it will be fully based on an online reader (instead of the VPN version of the bridging solution). At present, ILAE has a well-functioning online teaching course for EEG. After discussing this with the task force members and the president of ILAE, we decided to accept the proposal of the IFCN. In practical terms, this means that the costs of the joint EEG database will earliest show up in the budget for 2021.

Recommendations for Future Work

During 2020, the task force will work closely with Holberg-EEG on designing the web-based, interactive database for education and clinical research.

Report by Sándor Beniczky, Chair, Joint ILAE-IFCN EEG Task Force on EEG Databases

Leadership Development Task Force



Sheryl Haut



Jaideep Kapur

Commission Co-chairs

Sheryl Haut (USA)

Jaideep Kapur (USA)

Members

Helen Cross (UK)

Premek Jiruska (Czech Republic)

Samuel Wiebe (Canada)

Aims/Goals of the Commission

To train the next generation of ILAE leaders.

Commission Activities and Accomplishments

Leadership Development Course: The 4th ILAE Leadership Development Program was held June 21-22 in Bangkok, Thailand in conjunction with the 33rd ILAE International Epilepsy Congress. As indicated by participant evaluations, the program was a success. Similar to previous years, the course took place over one-and-a-half days and included a networking lunch with ILAE executives and other invited faculty and leaders. The 2019 program included 29 participants and incorporated small curricular modifications from previous years, including the addition of a session focused on building and leading collaborative studies. Since 2015, over 100 individuals have been trained.

Recommendations for Future Work

We plan the next course in conjunction with ILAE's North America regional convention in the fall of 2021.

Report by Sheryl Haut and Jaideep Kapur

Next Generation Task Force



Helen Cross



Christos Lisgaras

Commission Co-chairs

Helen Cross and Christos Lisgaras

Members

Maeike Zijlmans (Netherlands)

Marian Galovic (UK)

Sheryl Haut (USA)

Premysl Jiruska (Czech Republic)

Christos Lisgaras (Greece)

Rosa Michaelis (Germany)

Genevieve Rayner (Australia)

Aim/Goals

The Next Generation Task Force (NGTF) aligns activities from the ILAE Mentor Mentee program, the ILAE Leadership program, the Young Neurobiologists' Task Force, the ILAE-Young Epilepsy Section and any other initiatives aiming at the younger generation of people involved in epilepsy research, care, and allied health. All the above-mentioned initiatives are complementary to each other and target the next generation at different career stages. The overall goal of the NGTF is to promote the next generation in epilepsy research, care, and allied health and increase their involvement in the ILAE. To this end, the NGTF leadership has established the ILAE-Young Epilepsy Section (ILAE-YES), which currently numbers 400 members worldwide.

Commission Activities and Accomplishments:

Career Development

Mentor Mentee program

The ILAE Mentor Mentee program is an activity that was initiated at the IEC in Barcelona, and has since successfully been undertaken at ECE in Vienna and IEC in Bangkok, with 70+ individuals passing through the program. The latest program in Bangkok was successfully organized, with ongoing contact being maintained between some mentors/mentees.

Mentors and mentees were matched according to their expertise, considering a balanced geographical and gender representation. One of the highlights of the 2019 program was the joint reception with the ILAE-YES Peer-to-Peer Mentoring program, which will be replicated at future conferences, since the two programs are running in a complementary fashion.

ILAE-YES Peer-to-Peer Mentoring program

The inaugural ILAE-YES Peer-to-Peer mentoring program was launched at IEC in Bangkok, where mentors were early-career consultants and post-docs offering junior-level mentoring for the youngest congress participants. The first program started with a kick-off joint event with the ILAE Mentor Mentee program, followed by a dinner where junior mentors and their mentees had the opportunity to introduce themselves in a more relaxed atmosphere. Twelve pairs were selected to participate in the inaugural event, representing different regions and expertise. All participants received a formal certificate for their attendance and a survey is underway to identify points of improvement. The impact of the program was immediate. It increased the interaction and networking among peers, and was proven especially beneficial for the ones attending an ILAE conference for the first time. The program also complemented other ILAE-YES signature programs, such as career development and brainstorming sessions, poster tours and out-of-conference activities. The program was designed to establish a long-term relationship between the mentor and the mentee and, to this end, follow up communication is offered and encouraged through the ILAE-YES platforms and via face-to-face meetings at upcoming conferences.

Targeted conference program for young participants

Several new session formats and initiatives have been curated by the ILAE-YES group with the ultimate goal of attracting and engaging the next generation. Interactive brainstorming and career development sessions, poster tours, engaging panel discussions,

Next Generation Task Force *(continued)*

and out-of-conference activities attracted a sizeable number of conference attendees. During the 2019 term, six brainstorming sessions were organized covering different hot topics in epilepsy research, care, and allied health. Three career development sessions were held at IEC in Bangkok, aiming at advising young conference attendees on grant writing, cover letters, and abstract preparation. Two interactive YES sessions have been included in the 2019 IEC main program, covering career trajectories in epilepsy and cutting-edge research from young investigators in the context of the ILAE-YES Best Presenter Award session. All sessions were chaired by ILAE-YES members and supported by a panel of expert leaders in the epilepsy research arena. Similar format sessions have been organized at the Eastern Mediterranean and African Epilepsy congresses. The NGTF is in close collaboration with the Congress Council, where it has a formal representative and all Scientific Organizing Committees (SOCs) to curate the targeted conference program.

ILAE-Young Epilepsy Section

During the 2019 term, the ILAE-YES group has made significant strides by expanding its current general membership, leadership team, task forces, and regional chapters. In addition, the ILAE-YES team has opened up all leadership meetings to increase members' engagement and transparency in the decision-making process. The group is rapidly growing through its active participation at conferences, targeted online strategies, and the dedicated work of the six regional representatives who have coordinated the establishment of four ILAE-YES chapters (YES-Italy, YES-UK, YES-Japan, and YES-Canada). The ILAE-YES board has created formal procedures for the establishment of chapters and TF/Committee/SOC nominations to ensure proper governance and transparency. All these procedures have been shared with the general membership and approved by the ILAE-YES leadership team.

Public Outreach

The ILAE-YES group has curated content for ILAE social media in six different languages (Spanish, French, Portuguese, Japanese and Arabic, in addition to English) and has established new accounts in other social media domains. In addition, the ILAE-YES group is curating a bi-monthly newsletter which includes opportunities for jobs/training and the latest news. In 2019, the ILAE-YES group created the Interactive Media Task Force to meet the need for coordinating epilepsy-related content across different social media platforms. Additionally, the ILAE-YES infographics team in collaboration with the ILAE Education Council has curated educational content online in the form of an infographic that attracted the attention of more than 5,000 people online. Furthermore, the ILAE-YES group, in collaboration with the ILAE Wikipedia Epilepsy Initiative, has contributed nine Wikipedia entries exclusively developed by the ILAE-YES membership covering basic and clinical content, which are now in the final stage of uploading.

Collaborations with other ILAE Task Forces and Committees

Importantly, the NGTF and the ILAE-YES group have established fruitful links with other ILAE TFs, Committees, Councils and SOCs. NGTF members and/or ILAE-YES members are an integral part of the following ILAE bodies:

- ILAE Wikipedia Epilepsy Initiative
- Congress Council
- Young Neurobiologists Task Force
- Research Advocacy and Priorities Task Force
- Communications Task Force
- Education Council
- ILAE Europe Commission
- IEC/ECE/AOEC Scientific Organizing Committee
- Lancet Neurology Task Force
- Latin America Commission
- Neurobiology Commission
- North America Commission

Next Generation Task Force *(continued)*

Recommendations for Future Work

Future NGTF work will focus on:

1. Increasing ILAE-YES' involvement in 2020 conferences
2. Offering career mentoring opportunities at two different levels; peer to peer and senior to junior
3. Launching a signature ILAE-YES visiting scholarship program, piloting in Europe
4. Broadening ILAE-YES' reach by incorporating targeted communication strategies

Report by Helen Cross and Christos Lisgaras

Nosology and Definitions Task Force



Paolo Tinuper



Elaine Wirrell

Task Force Co-chairs

Paolo Tinuper (Italy)

Elaine Wirrell (USA)

Members

Edouard Hirsch (France)

Sameer Zuberi (UK), Past Chair

Management Committee Liaison

Samuel Wiebe (Canada)

Aims/Goals of the Commission

- Provide definitions for epilepsy syndromes
- Provide definitions and nosology of status epilepticus

Commission Activities and Accomplishments

Our Commission has had numerous Zoom meetings, as well as a large group meeting at the ILAE Conference in Bangkok. We are currently finalizing five papers which will summarize our work on definitions of epilepsy syndromes:

1. Methodology of Syndrome Identification
2. Syndromes in Neonates and Infants
3. Syndromes in Children
4. Syndromes in Teens, Adults, and Variable Ages
5. Core Genetic Generalized Epilepsy Syndromes

Recommendations for Future Work

We have identified the importance of recognizing etiology-specific syndromes, which may lead to precision therapies. This work will need to be expanded upon by a subsequent task force.

Report by Elaine Wirrell, Paolo Tinuper, and Eugen Trinka

Nursing Task Force



M. Prevos-Morgant

Chairs

Marielle Prevos-Morgant (Switzerland)

Members

Irene Elena Bonvehi (Argentina)

Eman Gannam (Saudi Arabia)

Melesina Goodwin (UK)

Mutinta Kanene Musikanga (Zambia)

Patty Osborne Shafer (US)

Dahua Zhang (China)

Karen Legg (Canada)

Management Committee Liaison

Sam Wiebe (Canada)

Extended Working Group:

Dominic Chartrand (Canada)

Marion Danse (France)

Clemence Ducourtil (France)

Claire-lise Bussien (Switzerland)

Yvonne Leavy (Scotland)

Zhan Qiongqiong (China)

Sarah Silk (Scotland)

Theo Teng (France)

Ivanna Yau (Canada)

Aims and Goals in 2019 – First Year of the Task Force (TF)

- To enhance nursing care worldwide by developing standardized nursing education for nurses in epilepsy
- To allow epilepsy nurses to optimise their clinical practice by sharing experiences and courses
- To empower our global epilepsy nursing community, increase epilepsy awareness, and improve patient outcomes
- September 2018 to January 2019: create the task force (eight members), define aims and goals

Activities and Accomplishments

- Published an article: "[Benefits of the epilepsy specialist nurses \(ESN\) role, standardized](#)

[practices and education around the World](#)," *Revue Neurologique*, 2019, Elsevier Masson

- First meeting by Skype in January 2019: State of the situation in different countries
- First meeting in June 2019 during IEC: Epilepsy nurses courses and program, new goals
- From September to December 2019:
 - Organized the first epilepsy nurse session and program, looking for sponsor
 - Development of the Epilepsy Nurses Network (nine members)

Plans for 2020 "Year of the Nurse and Midwife", WHO – Second Year of the TF

1. 7th July 2020: First epilepsy nurse special session during ECE in Geneva ([see programme](#))
Aims:
 - To develop an international epilepsy nurses professional network
 - To share experiences and projects
 - To develop epilepsy nurse courses
 - To propose a basic program on epilepsy nurse education**How to measure impact of activities:**
 - Increasing the number of attendees, delivery of courses to epilepsy nurses, satisfaction survey
2. Organize the second epilepsy nurse session (speakers) and program

Plans for 2021 – Third Year of the TF

1. San Servolo Epilepsy courses, July 2021
Aims:
 - To share experiences and projects on a specific topic
 - To improve coordination with doctors
2. Second ILAE epilepsy nurse meeting during IEC in Paris, August 2022
3. 2021-2022 Article (possible topic: A meaningful and usable program which could be delivered via various modalities depending upon local needs and resources)

Report by Marielle Prevos-Morgant

Research Advocacy and Priorities Task Force



Philippe Ryvlin

Chair

Philippe Ryvlin

Members

Shichuo Li (China), Past-chair
Martin Brodie (UK)
Faiza Fakhfakh (Tunisia)
Hector H. (Hugo) Garcia (Peru)
Natalia Gulyaeva (Russia)
Brian Hayes (Europe)
Abdullahi Ibrahim (Nigeria)
Richard Idro (Uganda)
Devora Kestel (USA)
Weiping Liao (China)
Terry O'Brien (Australia)
Carter Snead (Canada)
KP Vinayan (India)
Vicky Whittemore (USA)
Sam Wiebe (Canada)
Emilio Perucca (Italy)
Naluca Mwendaweli (Zambia), YES
Musa Watila (Nigeria), YES deputy
Pablo Casillas-Espinosa (Australia/LA), YES
Mohmad Farooq Shaikh (Malaysia), YES Deputy
Caroline Neuray (Austria), YES Deputy
Cristina Ruedell Reschke (Ireland), YES
Johann Sebastian Ortiz De la Rosa (Colombia), YES
Taylor Abel (USA), YES Deputy
Christos Lisgaras (Greece), YES, Deputy Leader

MC Liaison

Helen Cross (UK)

Task Force Aims/Goals

- To delineate and promote a strategy for increasing epilepsy research funding in the various world regions, in particular from public research agencies.
- To define epilepsy research priorities at the worldwide level.

Task Force Activities and Accomplishments

The task force has invited YES members from the different world regions to join and boost the task force activities. Two representatives per region (one primary representative and one deputy) were selected with the view that each region could be represented by one YES member at all task force meetings. Accordingly, the primary task force budget is aimed at sponsoring YES members to attend these meetings.

The task force met during the International Epilepsy Congress in Bangkok, and benefited from the presence and active participation of new YES members from all regions, whose main representative (Christos Lisgaras) accepted the position of Deputy Leader of the task force. The meeting helped participants understand the distinct expectations from representatives of the different regions. YES members insisted on the necessity to organize an international survey to best identify these needs and were happy to take a lead on this proposal. They also stressed the importance of greater opportunities to develop international collaboration, and proposed to create an online platform to facilitate such collaboration.

A task force meeting was planned during the AES but had to be canceled due to the last-minute cancellation of the task force chair's travel to the AES for personal reasons. Nevertheless, the YES task force members met informally and discussed how to pursue their objectives.

The Epilepsy Alliance Europe (EAE) joint ILAE-IBE Task Force (co-chairs P. Ryvlin, M. Brodie), acting on behalf of the Research Advocacy and Priorities Task Force at the EU level, organized as every year a meeting at the European Parliament in relation to the International Epilepsy Day. This was the opportunity to meet several members of the European Parliaments (MEPs) to further promote epilepsy research funding.

All activities related to epilepsy research priorities were passed on the ILAE/IBE endorsed Lancet Neurology Commission Task Force in charge of delivering a comprehensive report on this topic.

Research Advocacy and Priorities Task Force *(continued)*

Recommendations for Future Work

The incorporation of YES members into the task force has proven relevant and should be reinforced in the future. Indeed, and not surprisingly, YES representatives appear much more motivated than other task force members to consider the challenge of epilepsy research advocacy at the global level, and keen at developing tools and concrete action plans to this effect.

The specific activities successfully run in Europe through EAE over the last seven years are now on hold due to the lack of an available budget. EAE thus hope that changes in the management of the European Congress of Epilepsy will enable the task force to provide the resources required to continue its effective lobbying at the EU parliament.

Report by Philippe Ryvlin

Social Work Task Force



Jacob Mugumbate

Chair

Jacob Mugumbate (Zimbabwe)

Members

Rheana Nation (Australia)

Claudio Pulgar (Chile)

Chris Ryan (USA)

Task Force Aims/Goals

The overall goal of this new group will be to examine social work and epilepsy, and make recommendations for how the League can help move forward, with a global or international perspective.

The purpose of the task force is to design and recommend a plan with clear goals and steps to attract social workers to the ILAE, and encourage their participation in educational and scientific programs and publications.

Commission Activities and Accomplishments

The task force was formed and constituted this year to focus on specific allied health professions after the Allied Health Taskforce was disbanded. This year, we agreed on our future direction, which is guided by this strategy:

1. Map social work programs of relevance to epilepsy around the world with a view toward selecting those that ILAE could roll out to international populations.
2. Develop sessions/workshops at conferences that focus on psychosocial comorbidities.
3. Design a project to attract social workers to the ILAE.

Report by Jacob Mugumbate

Transition in Care from Childhood to Adult Task Force



Danielle Andrade

Chair

Danielle M. Andrade

Members

Jaime Carrizosa (Colombia)
Dana Craiu (Romania)
Rima Nabbout (France)
Makiko Osawa (Japan)
Puja Patel (USA)
Guido Rubboli (Denmark)
Maria Seddiqui (Qatar)
CT Tan (Malaysia)

MC Liaison

Helen Cross (UK)

Task Force Aims/Goals

Goal: To improve the process of transition from pediatric to adult care all over the world.

Specific Aims:

1. Understand the current situation in different regions of the world, in academic centers, and in communities.
2. Identify barriers for transition (local and global barriers).
3. Hear the needs of patients and their families regarding transition. This will be broken up into two groups of patients: those with epilepsy and normal intelligence (or mild learning disability) and those with epilepsy and moderate to severe intellectual disability.
4. Define minimal standards that can be incorporated into any setting or system.

Commission Activities and Accomplishments:

The commission members had two conference calls and met

twice face-to-face (June 2019 in Bangkok and December 2019 in Baltimore, USA) to discuss ongoing activities.

Main activities included:

- Determining what is the status of transition in different regions. To reach this goal, two questionnaires about availability and perceived barriers to transition programs were created and independently validated (one in Europe and one in South America). These questionnaires were aimed at health care workers.
- Another questionnaire asking patients, families, and caregivers about their experiences with transition and their perceived needs has been developed and validated.

Recommendations for Future Work

1. The first set of questionnaires were combined and will be distributed to ILAE chapters.
2. The patient/family questionnaires will be reviewed by the group and distributed to end users online.
3. The commission plans on gathering information from the second set of questionnaires to develop a Transition Toolkit to help patients and families move to the adult system, even when no structured transition program is present.

Report by Danielle M. Andrade

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 complex 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 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 involving the members of the Genetics Commission and the chairs of the associated task forces. In addition, we have held two face-to-face meetings; one at the 33rd International Epilepsy Congress in Bangkok (24 June 2019) and the other at the American Epilepsy Society Annual Meeting (8 December 2019). The meetings have provided the opportunity to coordinate the activities 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, and for support of the ongoing Epilepsioime and Sequencing Data Sharing initiatives.

Task Forces:

Clinical Genetic Testing in the Epilepsies Task Force

(Joint task force with the ILAE Diagnostics Commission)

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 continued to focus 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 currently working on three separate manuscripts to be finished in 2020, seeking to raise awareness and provide information on all these knowledge gaps.

Genetic Literacy Task Force

Co-chairs

Nigel Tan (Singapore)
Daniel Lowenstein (USA)

Members

Samuel Berkovic (Australia)
Peter de Jonghe (Belgium)

Genetics Commission *(continued)*

Ingo Helbig (Germany)
Jiang Yuwu (China)

Executive Committee Liaison
Helen Cross (UK)

The task force has continued to be very active in 2019, generating a new publication on the pharmacogenetics of adverse reactions of antiepileptic drugs. Another article on familial focal epilepsies is planned to appear in 2020. The task force has also started 'Phase 2,' with several manuscripts being planned to cover a wide range of topics, including:

- Genetic counselling
- Benign familial epilepsy syndromes
- Epilepsy with intellectual disability
- Malformations of cortical development with epilepsy
- Epileptic encephalopathies
- Progressive myoclonic epilepsies
- Structural lesions associated with epilepsy
- Sudden unexpected death in epilepsy (SUDEP)

They continue to maintain the online MCQ website ([sample quiz here](#)) so that readers can do self-learning immediately after reading, or days/weeks later to refresh their knowledge.

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.

Zhang Z, Wu Y, Tan NCK, Jiang Y, and the International League Against Epilepsy Genetics Commission. Genetic literacy series: clinical application of pharmacogenetics for adverse reactions to antiepileptic drugs. *Epileptic Disord* 2019;21:330-336.

Epilepsiome 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 (UAE)

Junior Members (curating ILAE classification within the Human Phenotype Ontology)

David Lewis-Smith (UK)
Ganna Balagura (Italy)
Hugh Kearney (Ireland)
Gordon Jing (China)

The Epilepsiome Task Force has continued to approach 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 is the 'Epilepsiome blog' (<http://epilepsygenetics.net/>), which remains the most frequently read resource for epilepsy and genes, with up to 10,000 unique visitors per month.

Another important activity of the task force has been gene curation, which has been carried out in collaboration with the ClinGen Epilepsy Clinical Domain Working Group. Gene curation for a 'first priority gene list' has been completed and published (Helbig et al., 2018) with a further publication pending. Another 19 genes have been curated since the initial publication (or are in progress). The final classification of each gene is published on the freely accessible ClinGen site (www.clinicalgenome.org).

The third activity of the task force has been the revision of the epilepsy-related Human Phenotype Ontology (HPO), a digital language for epilepsy phenotypes used by many research groups and clinical laboratories, which is completed as of 12/2019 and is currently integrated into the full HPO release to be available for the medical genetics and clinical community. The implementation of the revised Human Phenotype Ontology has been presented at several national and international meetings (Kearney et al., AES Abstract 3.387, 2019). Studies to test and demonstrate the value of the revised ILAE classification to better capture information on individuals with epilepsy is currently underway (Lewis-Smith et al., ECE abstract, submitted), using internal data and the clinical information of the Epi25 project.

Publication:

Helbig I, Riggs ER, Barry CA, Klein KM, Dymment D, Thaxton C, Sadikovic B, Sands TT, Wagnon JL, Liaquat K, Cilio MR, Mirzaa G, Park K, Axeen 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.

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)

The Consortium has made important progress finishing and publishing the second large-scale genome-wide association study (GWAS) in the form of a mega analysis in >15,000 individuals with epilepsy at the end of 2018 (ILAE Consortium on Complex Epilepsies. 2018). This study revealed 11 new loci, particularly for genetic generalized epilepsies, for which 30% of the heritability can now be explained by common risk factors. The third genome-wide meta-analysis involving >25,000 cases with epilepsy ('ILAE 3') is now being undertaken, driven largely by the Cleveland Clinic laboratory headed by Dennis Lal. Preliminary results were presented in a face-to-face Consortium meeting which was held during the American Epilepsy Society Annual Meeting (8 December 2019). Notably, the findings from the second analysis were also used to calculate polygenic risk scores for generalized and focal epilepsy, as detailed in a study headed by the Lal lab (Leu C et al. 2019). The study revealed differentiating factors for both major types of epilepsies, which might be used in the future in prediction tools.

Publications:

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.

Leu C, Stevelink R, Smith AW, Goleva SB, Kanai M, Ferguson L, Campbell C, Kamarani Y, Okada Y, Sisodiya SM, Cavalleri GL, Koeleman BPC, Lerche H, Jehi L, Davis LK, Najm IM, Palotie A, Daly MJ, Busch RM; Epi25 Consortium, Lal D. Polygenic burden in focal and generalized epilepsies. *Brain* 2019;142:3473-3481.

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)
Joshua Motelow (USA)
Sanjay Sisodiya (UK)

Genetics Commission *(continued)*

The newest of the task forces under the Genetics Commission, the Task Force on Sequencing Data Sharing was founded with the goal of bringing together as much sequencing data as possible from patients with genetic epilepsies across the world, and to make them available for the scientific community working on epilepsy genetics. Over the past 12 months, the task force has been working to establish a joint data repository in Luxembourg, and has planned which groups will be approached to collect exome data. The task force has also approached industrial companies (both pharmaceutical and genetic diagnostics companies) to discuss joint interests and opportunities for future funding for this initiative (face-to-face meeting at AES conference, December 8, 2019). The goal is to have this new platform running in 2020.

Report by Holger Lerche

The Lancet Neurology Commission



Philippe Ryvlin

Commission Chair

Philippe Ryvlin (Switzerland)

Members

Sándor Beniczky (Denmark)
Sam Berkovic (Australia)
Jeff Britton (USA)
Martin Brodie (Scotland)
Fernando Cendes (Brazil)
Edward Chang (USA)
Helen Cross (UK)
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Brandy Fureman (USA)
Aristea Galanopoulou (USA)
Jean Gotman (Canada)
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Akio Ikeda (Japan)
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Nathalie Jetté (USA)
Devora Kestel (USA)
Heung Dong Kim (South Korea)
Katja Kobow (Germany)
Sam Lhatoo (USA)
Rosa Michaelis (Germany)
Caroline Neuray (Austria)
Terry O'Brien (Australia)
Page Pennel (USA)
Emilio Perucca (Italy)
Mary Secco (Canada)
Michele Simonato (Italy)
Sanjeev Thomas (India)
Eugen Trinko (Austria)
Kette Valente (Brazil)
Vicky Whittemore (USA)
Sam Wiebe (Canada)
Karen Wilcox (USA)
Jo Wilmshurst (South Africa)
Sarah Wilson (Australia)

Aims/Goals of the Commission

To establish a comprehensive report on research priorities in epilepsy, to be published in *The Lancet Neurology*.

Commission Activities and Accomplishments

The Task Force (TF) was set up in late 2018, and then endorsed by both *The Lancet Neurology* and the ILAE.

It includes 32 members, with optimal gender balance and appropriate representation of main research topics and world regions.

Most TF members are Chair, Co-chair, or Past-chair of other ILAE commissions or TFs.

The TF held three videoconferences during the first half of 2019, with the view to delineate the summary and main topics of the report.

A full-day meeting was then organised during the International Epilepsy Congress in Bangkok, during which the framework of the report and detailed contribution expected from each participant was delineated.

Contributors to this report are currently finalizing their sections with the hope to submit a final draft to *The Lancet Neurology* before summer.

Recommendations for Future Work

The report shall provide a strong basis for defining the future strategy of the Research Advocacy and Priorities Task Force, and help lobbying research-funding agencies as well as other organisations (including WHO) to further support epilepsy.

Report by Philippe Ryvlin

Medical Therapies Commission



Kimford Meador



Dong Zhou

Co-Chairs

Kimford J. Meador (USA)
Dong Zhou (China)

Members

Patrick Kwan (Australia)
Sanjeev Thomas (India)
Tim Welty (USA)

Management Committee Liaison

Emilio Perucca (Italy)

Aims/Goals of the Commission

The aims of the Medical Therapies Commission are to serve the goals of the ILAE related to medical therapies:

1. To advance and disseminate knowledge about epilepsy,
2. To promote research, education, and training,
3. To improve services and care for patients, especially by prevention, diagnosis and treatment.

Goals of the individual task forces of our commission are below.

Access to Treatment

The task force (TF) plans to conduct a research initiative that will have several outputs including:

1. An international database of projects, initiatives, and interventions that improve access to AEDs.
2. A validated evaluation and scoring tool for projects.
3. An evaluation of completed and ongoing projects in ILAE member countries.
4. Selected in-depth case studies of showcase projects that can be published and used as models for other countries to implement, and for funding agencies to scale up.

Botanicals & Traditional Medicines

Expand website with listing and description of multiple botanicals. Explore information on traditional medicines.

Dietary Task Force

1. To promote and establish the use of the ketogenic diets, particularly in countries with limited resources.
2. To provide standardized guidelines regarding ketogenic diets and its variants.
3. To advance and disseminate knowledge about the ketogenic diet.

Elderly

Define the scope of the problem, select educational goals, and identify areas needing research.

Emergency Treatment

The goals of the TF on Emergency Treatment is to produce two evidence-based guidelines:

1. European guidelines in conjunction with the EAN.
2. Guidelines for resource poor countries. Both will follow the GRADE Methodology.

Generic Medications

1. Review literature related to generic substitution of antiseizure medications.
2. Review issues related to safety and reliability of generic drugs in various countries, especially resources limited countries.
3. Develop products that inform and assist ILAE members in making decisions about generic substitution of antiseizure medications.

Psychology

1. Investigate barriers to the delivery of psychological care in patients with epilepsy in different nations.
2. Collaborate with the Psychiatry Commission to develop educational input for international epilepsy curriculum that relates to psychological and psychiatric topics.

Regulatory Affairs Task Force

1. Reduce placebo exposure in AED trials by implementing new endpoints (time to event).

Medical Therapies Commission *(continued)*

2. Further develop the possibilities of extrapolating data from one age group to another.
3. Interact with the European Medicine Agency in the elaboration of their new guideline for antiepileptic drugs.
4. Elaborate new study endpoints for epileptic encephalopathies and specific diseases.
5. Pursue progress on regulatory trials for status epilepticus.

Women/Pregnancy

1. Improve our understanding of the availability globally of recommendations for the management of epilepsy in women of childbearing potential.
2. Provide women with epilepsy of childbearing potential easy access to updated information of relevance for their treatment.

Commission Activities and Accomplishments:

Activities and accomplishments of the individual task forces of the Medical Therapy Commission are presented.

Access to Treatment

1. The task force conducted a global survey: "Access to AEDs." Data was collected from 110 countries (100 National Chapters + Caribbean Chapter with 10 countries represented), 81% countries in ILAE&IBE, 56% countries in the World HIC: 39 (38,6%), UMICs: 27 (26,7%), LMICs: 25 (24,8%), LICs: 10 (9,9%). The preliminary data was presented at the IEC in Bangkok (June 2019) and it was further discussed during the TF meeting held at the IEC. Unfortunately, it was impossible to analyze data concerning AEDs prices. In order to get this data, another specific form was sent to all ILAE Chapters which responded to the survey on December 2019 (deadline: 15 January 2020). Data analysis and writing of the manuscript with the survey results will start as soon the data on AEDs prices is collected. We plan to have the discussion of the final draft of the manuscript during the TF

Meeting at ECE in Geneva (July 2020).

2. Parallel survey for Africa: In order to fill the gap of information from the African Continent (LMIC/LICs), during the TF Video Conference on November 2019, it was decided to do a parallel survey for Africa using a slightly modified version of the survey questionnaires. The survey will be sent to one neurologist/epileptologist (working in tertiary care/university hospitals) and the two first level hospitals (one in an urban setting, one in a rural setting) which are indicated by the neurologist in each African country.

Botanicals & Traditional Medicines

1. The task force continues to work on expanding its website information, which has listings and descriptions of multiple botanicals and traditional medicines. They are now working to get approval of the website information by the ILAE and have it linked to the ILAE website.
2. Task force Co-chair Dr Elsas participated in a Germany/Austria/Switzerland regional epilepsy conference entitled, "Symposium: Cannabidiol as Treatment for Epilepsy – Recent Developments" in Basel, May 8-11, 2019.
3. The first botanical antiseizure medication, cannabidiol, was approved in the USA (Epidiolex) and Europe (Epidyolex).

Dietary Task Force

The Dietary Task Force held two educational initiatives and one workshop in 2019:

1. First educational initiative: The Ketogenic Diet Symposium Shenzhen China & CME Paediatric Neurology Shenzhen on July 26-28 in China;
2. Second educational initiative: Dietary Therapies for Epilepsies - Ketogenic Diet Workshop on Sept. 26-28 in the Philippines;
3. Workshop: The Third Pediatric Neurology School - Ketogenic Diet in the Treatment of Epilepsy in Children on Oct 3-4 in Uzbekistan.
4. Many of the dietary TF members are participating together with the organizing committee for the "7th

Global Symposium for Medical Ketogenic Dietary Therapies,” which will take place in Brighton, UK from Oct 6-10, 2020.

Elderly

The task force on Elderly and Epilepsy conducted an initial content review of epilepsy-related websites and found that content on epilepsy in the elderly was either minimal or hard to find.

The group is also conducting a literature review collecting and sharing of references in order to prepare a review manuscript. Dr Faught spoke on "Epidemiology and Drug Treatment of Epilepsy in the Elderly" at the Epilepsy Society of Australia in November 2019.

Emergency Treatment

The task force has been working with EpiCARE (European Reference Network for Rare and Complex Epilepsies) to identify areas where development of needed epilepsy guidelines is needed, and then to develop these clinical practice guidelines and monitor them to assess adherence and impact. One of the critical areas chosen is treatment of status epilepticus. After critical appraisal, new guidelines will be formulated and submitted to the ILAE ExCo and the EAN for final approval.

Generic Medications

Generic Task Force conducted an international survey which demonstrated poor knowledge of generic products, less education in lower income countries, concerns with quality and regulatory control, greater concern in lower income countries, and for specific products. Also, the survey revealed issues related to access to medications. The task force presented preliminary findings from this survey in an AES abstract in 2019.

Psychology

1. All-day TF meeting: The TF met for an all-day meeting at the IEC in Bangkok this year.
2. Interactive forum session at IEC: The TF ran an interactive forum session at the IEC in Bangkok to present and discuss case-based educational activities that relate to the International Epilepsy Curriculum.

3. Submission of IEC 21 session proposal: The discussion at the forum session led to the submission of an IEC 21 session proposal entitled “Suicide and Seizures - Suicide Management in Routine Clinical Epilepsy Care: Equipping Health Care Providers”.
4. ILAE webpage offering mental health care resources: The TF designed an ILAE webpage to provide mental health care resources, e.g. free downloadable screening tools for depression and anxiety for adults and children.
5. Online survey of barriers to psychological treatment in PWE complete: The TF successfully ran an international survey to investigate barriers to psychological treatment in PWE. The results of the survey will be analyzed and published in 2020.
6. Update of Cochrane review, “Psychological Treatments for PWE”: This Cochrane review is a priority review due to the update of the NICE guidelines on epilepsy. The TF has therefore created and submitted an update of the review.
7. Input to online case-based International Epilepsy Curriculum: Christian Brandt and Rosa Michaelis co-coordinated input addressing psychosocial and psychiatric issues (e.g. counseling of anxious parents, screening for depressive symptoms, etc.). So far, five members of the Psychiatry Commission and Psychology TF have provided input to all six cases that have already been developed.

Regulatory Affairs Task Force

This year was focused on two things. The first was the issue of infant epilepsy. We designed and wrote a novel design which was published as an ILAE report (Auvin S, French J, Dlugos D, Knupp KG, Perucca E, Arzimanoglou A, Whalen E, Shellhaas RA). Novel study design to assess the efficacy and tolerability of antiseizure medications for focal-onset seizures in infants and young children: a consensus document from the regulatory task force and the Pediatric Commission of the International League against Epilepsy (ILAE), in collaboration with the Pediatric Epilepsy Research Consortium (PERC). *Epilepsia Open*. 2019 Sept 4;4(4):537-543). The design was also used as a post-hoc analysis of fenfluramine that was presented at AES, which demonstrated that the de-

sign would have been successful using real data. Our second task this year was to respond to the draft EMA guidelines that are under review at the present time. Our next meeting will be with the EMA in Vienna at the European Congress.

Women/Pregnancy

The global survey of existing guidelines and recommendations for the management of women with epilepsy during pregnancy was completed. The results were presented at a session on pregnancy organized by the TF at the Bangkok IEC in June 2019. At the same session, members of the TF also gave an update on neurodevelopmental outcomes after exposure to antiseizure medications, and on the practical management of epilepsy in pregnancy in resource-limited settings. The TF has published a full-length expert opinion report in *Epileptic Disorders* on the management of epilepsy in pregnancy. An executive summary of the same report was published in *Epilepsia*. A discussion with ILAE's Wikipedia team has been initiated, with the aim to develop a Wikipedia posting based on the *Epileptic Disorders* publication, and to also to make the full-length report available through Wikipedia. In December 2019, the TF had a full day meeting in conjunction with the Annual AES meeting in Baltimore, setting the goals for its activities during 2020.

Recommendations for Future Work:

Plans for the individual task forces of the Medical Therapy Commission are presented.

Access to Treatment

1. The task force began a survey one year ago involving more than 100 countries. It will continue analyses of this data. Unfortunately, it was impossible to analyze data concerning AED's prices. In order to get this data, another specific form was sent to all ILAE Chapters which responded to the survey in December 2019 (deadline: 15 January 2020). Data analysis and writing of the manuscript with the survey results will start as soon the data on AED's prices is collected. We plan to have the discussion about the final draft of the manuscript during the TF Meeting at ECE in Geneva (July 2020)

2. Parallel survey for Africa: In order to fill the gap of information from the African continent (LMIC/LICs), during the TF video conference in November 2019, it was decided to do a parallel survey for Africa using a slightly modified version of the survey questionnaires. The survey will be sent to one neurologist/epileptologist (working in tertiary care/university hospitals) and two first-level hospitals (one in an urban setting, one in a rural setting), which are indicated by the neurologist in each African country.
3. Ultimately, the task force plans to publish the data on an international journal.
4. A session proposal for ICE Paris 2021 on Access to Epilepsy Care has been presented.

Botanicals & Traditional Medicines

The task force will continue its work on expanding its website information, which has listings and descriptions of multiple botanicals and traditional medicines. They are now working to get approval of the website information by the ILAE and have it linked to the ILAE website. One of the group's members, Dr Ekstein, will be co-author of a chapter entitled, "Botanicals and Complementary Treatments," in the book "Personalized and Stratified Therapy in Epilepsy" in 2020.

Dietary Task Force

The Dietary Treatments Task Force has proposed to organize workshops and help neurology centers set up a ketogenic diet clinic by providing essential lessons regarding the ketogenic diets. These workshops will take place in Pakistan, Kazakhstan, Malaysia, Iran, South Africa, and Taiwan.

Elderly

The task force plans for the next year include:

1. Task force meeting, Geneva July 5 2020.
2. Writing three reviews with recommendations for future research on the following topics: Epidemiology- Faight, Beghi, Leppik, Diagnosis and Etiologies- Akamatsu, Cretin, O'Dwyer, and Treatment and Prognosis- Kwan, O'Dwyer, Kraemer.

Medical Therapies Commission *(continued)*

3. The task force plans to make a more systematic review of websites to identify good content on 'Epilepsy and the Elderly' in order to offer better content to pertinent websites.
4. 'Epilepsy in the Elderly' was requested as a main theme at the IEC 2021.
5. The task force is offering to give talks on 'Epilepsy and Elderly' at meetings other than neurological meetings (e.g., American Academy of Family Physicians, American Society of Internal Medicine).
6. Dr Leppik will speak at the US Long Term Care Association on "Epilepsy in Nursing Homes" in April 2020.
7. Drs Faught and O'Dwyer will be writing an article on pharmacotherapy of epilepsy in the elderly for *Drugs and Aging*.

Emergency Treatment

The task force will continue its work with EpiCARE to develop guidelines for the treatment of status epilepticus. After critical appraisal, new guidelines will be formulated and submitted to the ILAE ExCo and to the EAN for final approval. New European guidelines (with the EAN) shall be published in *Epilepsia* and *E J Neurology*, and guidelines for the resource-poor countries shall be published in *Epilepsia*. Later, the group plans to monitor guideline adherence and impact.

Generic Medications

The Generic Medications Task Force is working to refine their survey and working with the Access to Treatment Task Force to seek new information. The Generic Task Force plans to publish the results of its survey and is working on the development of a manuscript that will serve an informational and educational basis for understanding generic substitution. The group also submitted a proposal for a major session on generic substitution at the ILAE Congress in 2021. They will continue to collaborate with Access to Treatment Task Force.

Psychology

The Psychology Task Force will continue to conduct a web-based survey to assess barriers to psychological care in different ILAE chapters. They will collaborate with the

Identification, Treatment and Prevention TF (Psychiatry Commission) on the development of specific strategies to address the identified barriers. The Psychology TF also plans a publication of results session at IEC 21. The Psychology TF and Psychiatry Commission plan to offer ongoing input to international epilepsy curriculum informed by the results of the survey.

Regulatory Affairs Task Force

Because clinical trials for new AEDs in children age one month to four years have become unfeasible, and have ethical concerns, the task force has designed and published a new trial design in infants. It was submitted to the EMA (Pediatric Committee, CNS Working Party and CHMP). The revision of the EMA guidelines on epileptic disorders has been put on hold because of the move of the Agency from London to Amsterdam; they are planning to resume their guideline-related activities by the end of 2019, and the new revised guidelines will be enforced by then. Because of the postponing of the EMA guidelines activities, these discussions and their outcome must be followed-up on. The TF will meet with EMA during the next European Congress on Epileptology (Geneva July 2020). In regards to the FDA, the annual Research Roundtable for Epilepsy (14-15 May 2020) is our only opportunity to meet with the FDA; thus, we will focus on seizure types and epilepsy syndromes, and how to classify patients in studies to make them more representative of the general populations.

Women/Pregnancy

The TF will continue to develop new expert opinion papers on relevant topics for *Epileptic Disorders* and subsequently for Wikipedia. For 2020, we plan to deliver a similar manuscript on breastfeeding and antiepileptic drugs. To facilitate these goals TF teleconferences as well as in person meetings will be conducted in conjunction with ECE and AES for those members attending the conferences.

Report by KJ Meador, consolidating reports from task force leaders.

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 face-to-face meetings at the International Epilepsy Congress (IEC) in Bangkok (June 22nd, 2019). The following activities were held in 2019:

- A **neurobiology symposium** was held during the IEC in Bangkok on “*Biological Rhythms that Modulate the Risk of Seizures*,” chaired by Christophe Bernard and Aristeia Galanopoulou on June 23, 2019. The symposium included lectures on rhythms modulating seizure risk (Maxime Baud), circadian control of seizures and seizure forecasting (Philippa Karoly), circadian regulation in the pathophysiology and treatment of temporal lobe epilepsies (Christophe Bernard), and the loss of *CLOCK* in focal epilepsies (Judy Liu).
- The 2019 **Harinarayan Young Neuroscientist Awards** were given to young epilepsy researchers with the best basic and clinical research presented at the IEC. The NBC members selected Gautham Bhargava (India) and Sarah Buck (United Kingdom) as this year’s awardees. Mr. Bhargava is a PhD candidate, and reported his findings on the potential of phase amplitude coupling of low frequencies with high frequency oscillations to localize epileptogenic zone in magnetoencephalography. Dr. Buck presented her findings on dynamic changes in episodic memory functional connectivity after temporal lobe resections.
- The NBC instituted for the first time the **Neurobiology Commission Bursaries**, which are awarded after competitive selection to young investigators, to provide support for attending scientific meetings or visiting training fellowships that will help expand their skills in epilepsy research and care. In 2019, four applicants were selected to receive bursaries to attend scientific meetings (Annick Melanie Magnerou, Ashwini Sri Hari, Victor Navarette Modesto, and Lionel Nyamurenje). In addition, three bursaries were awarded for visiting fellowships (Amit Agarwal, Thomas, and Amartey Tagoe). The initiative was well-received based on the number of applications, and the feedback by the awardees and a new cycle is planned for 2020.
- The NBC received several applications seeking **sponsorship of scientific workshops or training courses** with relevance to epilepsy. The following activities were selected by the NBC and proposed for financial sponsorship by the ILAE, based on their content, educational and scientific merit, and relevance to the strategic and educational goals of the ILAE and NBC: (a) San Servolo Epilepsy Course, 2020: Bridging Basic with Clinical Epileptology – Accelerating Translation in Epilepsy Research (July 20-31, 2020, San Servolo, Italy), (b) Gordon Research Conference and Seminar on Mechanisms of Neuronal synchronization and excitability (August 15-21, 2020, Spain), (c) Latin America Workshop on Neurobiology of Epilepsy (May 23, 2020, Medellin, Colombia), (d) Post-

Neurobiology Commission *(continued)*

traumatic Epilepsy, models, common data elements and optimization (June 11-12, 2020, Bethesda, MD, USA). The final decisions are currently pending final review by the ILAE.

WONOE 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 WONOE meetings prior to the IECs.

The **2019 Workshop on Neurobiology of Epilepsy (WONOE 2019)** was organized with the theme of “*What is a seizure?*” The workshop took place at the Krungsri River hotel in Ayutthaya, Thailand (June 16-20, 2019), thanks to generous financial support from the ILAE, the Harinarayan Family, and the UCB. This year, the WONOE was dedicated to Uwe Heinemann, who was one of the founders of the workshop and an integral contributor to the success of WONOE over the years. The keynote WONOE lecture was therefore named “Uwe Heinemann Keynote Lecture.” Forty participants were selected to attend, with international representation and a mixed preclinical, basic science and clinical epilepsy expertise. The sessions included presentations of original research and discussions, which are currently being prepared for submission for publication. To facilitate the attendance of young investigators, the WONOE TF awarded four bursaries, named “*Raman Sankar WONOE Bursaries*,” to honor the continuous fundraising efforts by Professor Sankar for this workshop. The awardees were: Pablo Casillas-Espinosa, Diego Jimenez-

Jimenez, Hiroki Nariai, and Jennifer Wong.

The NBC and WONOE TFs were approached by young investigators to support the organization of regional WONOE meetings in the Latin American region, encourage the engagement of young epilepsy researchers in neuroscience, and increase their presence and participation in the regional neuroscience and epilepsy meetings. Given the relevance of this initiative to the mission of the NBC and WONOE TF, the TF members unanimously voted to support the organization of a planning workshop that will help identify the needs, formulate the infrastructure, and plan for such a future workshop in Latin America.

ILAE/AES Joint Translational TF

Members

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

TF. Multiple zoom conferences, as well as two face-to-face meetings, were organized in Bangkok (IEC, June 2019) and Baltimore (AES meeting, December 2019). The TASK1-WGs have started their work towards the creation of an online atlas of rodent EEGs, a system for the interpretation of the rodent EEGs, and classification of seizures and epilepsy models in rodents. TASK2 is continuing the systematic review of outcome measures in epilepsy models.

Neurobiology Commission *(continued)*

TASK3-WGs are working toward the creation of additional common data elements and case report forms for general pharmacology studies, models used for the development of epilepsy therapies, epilepsy phenotyping, omics, imaging, pathology, and electronic databases. CURE (Citizens United for Research in Epilepsy) has offered to co-sponsor the efforts to create electronic modules of the case report forms which are currently created by LONI at the University of South California. Several reports are being planned on the activities of the various WGs.

Genetics/Epigenetics TF:

Chair

David Henshall (Ireland)

Members

Katsuhiko Yamakawa (Japan)

Albert Becker (Germany)

Chris Reid (Australia)

Alica Goldman (USA)

Erwin van Vliet (Netherlands)

Iscia 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

During 2019, the Epigenetics-Genetics TF worked on four of its five original tasks. Under Task I, Publications,

the TF had its first paper accepted for publication, entitled “Epigenetics explained: A report of the Genetics/Epigenetics Task Force and topic “primer” for the epilepsy community” which was co-written by the entire membership and will be published in *Epileptic Disorders**. The paper is designed to provide a broad, but nevertheless substantial, overview of the topic and includes explanations and definitions, the main epigenetic mechanisms, evidence for these as contributors to mechanisms of epilepsy, and future directions of the field. Planning for the next publication, based on how mutations in genes with known epigenetic functions cause epilepsy, is underway. Work also included liaising with other task force chairs to identify gaps and avoid duplication of efforts.

Under Task II, Promoting the Topic, the TF led submissions for symposia, and provided speaker suggestions for various major meetings, and were successful in the inclusion of the topic at several key meetings, including the 2020 Gordon Conference and 14th European Congress on Epileptology. Applications to the IEC in Paris, 2021 are under review. We began work on developing suitable material about the topic for inclusion on ILAE and related websites such as a “Wiki” page on epigenetics.

Under Task III, Training Activities, the TF is planning a workshop on epigenetic methods for the epileptologist, to be hosted by ICL in the UK. The TF collaborated with the YES (Young Epilepsy Section) Task Force on the topic of climate change, discussed how members can implement more sustainable research practices, and is participating in a planned first-ever “virtual” epilepsy conference being hosted by UCL in 2020.

Under Task IV, Activities on Resources and Infrastructure, members of the TF are working on the development of common data elements for preclinical research. This will now include a specific module for collecting “omics” data.

*Publications

Katja Kobow, Christopher A. Reid, Erwin A. van Vliet, Albert J. Becker, Alica M. Goldman, Shinichi Hirose, Iscia Lopes-Cendes, Hela Mrabet Khiari, Annapurna Poduri, Michael R. Johnson and David C. Henshall. Epigenetics Explained: A topic “primer” for the epilepsy community. A report of the Genetics/Epigenetics Task Force. *Epileptic Disorders*, Accepted.

Neurobiology Commission *(continued)*

Young Neurobiologists TF:

Chair

Premysl Jiruska (Czech Republic)

Members

Joseph Raimondo (South Africa)

Kathryn 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 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 with the initiatives and goals of the NBC and its TFs.

Activities

In 2019, the TF continued activities focused on attracting, sustaining, and advancing young neurobiologists. TF members have explored the possibilities of promoting education and training in epilepsy research by creating undergraduate and postgraduate programs to train epilepsy research specialists of the 21st century.

One opportunity is the European Universities Initiative, set up by the European Council and the European Commission. This initiative aims to create pan-European high-quality curricula on specific topics. The curricula should have

following features: a flexible and personalized curriculum with embedded mobility leading to a degree; innovative pedagogies with a challenged-based transdisciplinary approach to foster entrepreneurial mindsets and civic engagement; enhanced staff mobility between partner institutions to teach/do research and equip students with a broad range of forward-looking skills. The initiative could represent an opportunity where ILAE could support creating a Master's program on Epilepsy. This program would be available to students from all over the world. It would cover various aspects associated with epilepsy, ranging from science and clinical epileptology to social, ethical issues, etc. Such a training program would represent a systemic approach/solution on how to recruit future epilepsy scientists. The TF has initiated initial negotiations about the possibility of opening the undergraduate program with representatives of the 4EU+ Alliance who are involved in European Universities Initiative.

Another possibility for creating future epilepsy leaders that warrants attention is the Marie Skłodowska-Curie Innovative Training Networks, which aims to train a new generation of creative, entrepreneurial, and innovative early-stage researchers. Recently, a consortium composed of multiple European epilepsy research laboratories, led by Dr. de Curtis from the NBC, submitted a proposal for an international Ph.D. training program in epilepsy. The proposed network brings together world-leading scientists and teachers in epilepsy, neurology, neuroscience, genetics, and a myriad of other fields. One of the core strengths of the program is the training of students in a systems approach to thinking and solving problems. This program could represent a foundation for future Ph.D. training under the auspices of ILAE.

We continued our collaboration with the Next Generation Task Force (NGTF), Leadership Task Force, Congress Council, and especially with the Young Epilepsy Section (YES). Liaisons from YNTF regularly participate in teleconferences of these groups. Here, YNTF members keep advocating for basic science and neurobiology, and provide valuable advice about various aspects related to experimental epilepsy research. NGTF and YES, with the strong support of YNTF, propose the opening of five fellowships for short-term visits at clinical centers or basic science laboratories.

Neurobiology Commission *(continued)*

Advocacy TF of the NBC

Co-Chairs

Raman Sankar (USA)

Solomon (Nico) L. Moshé (USA)

Members

Terence O'Brien (Australia)

Vicky Whittemore (USA)

Akio Ikeda (Japan)

Janet Mifsud (Malta)

Kathryn Davis (USA)

Management Committee Liaison

Ed Bertram (USA)

In 2019, the TF submitted two blogs on the *Living Well with Epilepsy* website. The TF is mindful to highlight content that relates to women who are the typical users of this site or the caregivers for people with epilepsy. In addition, an ILAE Neurobiology Commission email has been established for the blog. The TF has published content developed with Dr. Astrid Nehlig related to Caffeine in Epilepsy. Another article focused on climate change and how this might affect people with epilepsy, and was developed with Dr. Sanjay Sisodiya. To increase the coverage of epilepsy advances that would be useful for the general public to learn, there is a plan to recruit a medical writer and collaborate with the editorial board of the open access ILAE journal, *Epilepsia Open*, to highlight published research in lay language.

Aims

To evaluate the current funding environment for neurobiology research in epilepsy. To advocate for the value of neurobiology research toward improving knowledge on 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.

Report by Aristeia Galanopoulou, MD, PhD, Neurobiology Commission Chair

Activities

Initial work has focused on giving the epilepsy patient and caregiver community access to translational neurobiology research. The TF initially decided to work with *Living Well with Epilepsy*, a blog run by Jessica Kennan Smith. Kate Davis has been leading this effort. The TF is now in discussions on how to consistently develop content in lay language to bring new scientific findings to patients and the caregiver community.

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 primarily guided by the operations of four Task Forces. A description of the 2019 activities of the Pediatric Commission and all related Task Forces (TFs) is found below. In addition, the ILAE Pediatric Commission continues its involvement with the PET course dissemination (see below after the TFs reports).

The ILAE Pediatric Commission has continued its involvement in the discussion and work of the Nosology TF for the definition of the epilepsy syndromes (Elissa Yozawitz, Jo Wilmshurst, Stéphane Auvin). The interactions of the Commission with the regulatory affairs the TF initiated last year have resulted in a publication in *Epilepsia Open*. This paper is a proposal for a new design to investigate anti-seizure medications in infants (Auvin et al. [Epilepsia Open 2019; 4:537-543](#))

The report of each TF is written below, and they are followed by a report on the PET course:

Neonatal Seizure Task Forces

Neonatal Seizure Guidelines Update Task Force (Co-chairs: Ronit Pressler & Hans Hartmann)

The ILAE's Pediatric Commission set up a task force to update the guidelines on neonatal seizures, which were published jointly by the WHO and the ILAE in 2012. Seizures affect at least 2 in every 1000 neonates. They often are signs of a severe acute health problem, but also

significantly contribute to the morbidity and mortality of both term and pre-term neonates. As of today, only very few high-quality studies have addressed the optimal diagnosis and treatment of neonatal seizures.

Having finished the literature search, the task force 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. Professor 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 Professor Jo Wilmshurst from Cape Town (SA) speaking on 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 Professor Martha Feucht from Vienna (AUT) and Professor Stéphane Auvin from Paris (FRA).

Work on the evidence profiles currently continues and following completion of the systematic literature review, the task force aims to draft the guidelines in 2019.

Neonatal Classification Task Force (Co-chair: Ronit Pressler)

The Task Force on Neonatal Seizures has created a classification for seizures in the neonate, which is based on the 2017 ILAE Classification of Seizures and Epilepsies, but modified for seizures in the neonatal period. As part of the approval and adoption process, the League published the manuscript on the ILAE website and asked its members to review and comment on the proposed classification (<https://www.ilae.org/guidelines/definition-and-classification/neonatal-seizure-classification>). A total of 72 comments from the international community and *Epilepsia* reviewers were received and over the last year reviewed by an independent second task force. The Neonatal Classification

Pediatrics Commission *(continued)*

Task Force met at the 2019 IEC and discussed the comments. The manuscript of the proposed classification is currently adapted in line with the suggestions from the community with the aim to finalize the proposal by March 2020.

The TF successfully submitted a seminar proposal for the ICNC in October 2020 (San Diego) where Ronit Pressler & Hans Hartmann will present findings of the Neonatal Classification Task Force and the Neonatal Seizure Guidelines Update Task Force.

Medical Therapy Task Force (Chair: Lieven Lagae)

The aim of this task force is to review the current treatment options in young children with epilepsy (<4 years old), in order to stress the need for more evidence-based data. It will also be clear that most AEDs used in that age group are prescribed off-label. We will focus on six typical scenarios and review the current literature. In addition, a worldwide survey will be done to understand common treatment strategies. The six typical scenarios are based on the following clinical situations: 1. Febrile seizures; 2. Epileptic spasms; 3. Dravet syndrome; 4. Tuberous sclerosis; 5. Acquired structural lesion in the neonatal period; 6. Presumed genetic epilepsy with focal seizures.

In 2020, a survey with specific questions about first- and second-line treatment will be sent around and will result in a paper describing the most common practices. It is anticipated that the commonly used AEDs are prescribed without clear efficacy evidence in the younger children and that most of them are prescribed off-label. A second paper will review the existing literature on treatment in these six specific scenarios. Review strategies have been discussed in the working group and we hope to have both papers ready by the end of 2020.

Research Advocacy Task Force (Chair: Pauline Samia)

The Research Advocacy Task Force had a productive year in 2019. We planned and successfully conducted various activities, including:

Research Advocacy Workshop

Bangkok, 25th June 2019 at the 33rd International Epilepsy Congress

The Research Advocacy Workshop was held during an early morning session that was well attended and the audience included Professor Anannit Visudtibhan, President, ILAE Thailand Chapter. Jo Wilmshurst described challenges with access to care in low- and middle-income countries and outlined availability of medications, trained personnel, and other regional challenges as contributors. She indicated more research, specifically related to children with epilepsy across aetiologies, co-morbidities, management, and outcomes is needed. Pauline Samia elaborated on the challenges to research in low- and middle-income countries including lack of mentorship, and institutional and governmental facilitation. She highlighted a recent review of data on epilepsy from Kenya that re-affirmed the ongoing need for better public awareness of epilepsy as a treatable disease and for national-level action which targeted both prevention and management of epilepsy. Stéphane Auvin elaborated on strategies for developing sustainable health research capacity in low and middle-income countries, and included findings from a prospective, qualitative study which evaluated barriers and enablers to locally led clinical trials.

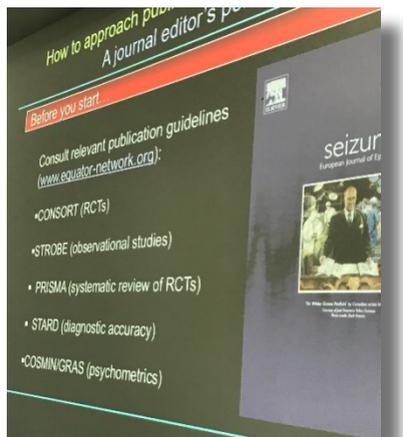
Research Advocacy Workshop

Entebbe, 24th August 2019 at the 4th African Epilepsy Congress

A workshop similar to the one held in Bangkok was organized during the AEC, and this one also generated considerable interest, leading to a full registration.



Additional speakers included Edward Kija, who pointed out challenges that researchers in epilepsy working in LMIC countries encounter in accessing funding, as well as the limited opportunities that currently exist for collaboration due to diverse clinical practice and regional demographics.



Joseph Raimondo's topic on basic neuroscience research in Africa, to inform the clinical management of status epilepticus, was an eye-opener to many about the possibility to conduct basic science research even in LMIC, and contribute to strategies to manage epilepsy. Markus Reuber led a session on "How to publish your research," which was well received and allowed many attendees to better understand how to identify suitable journals for their research and interact with editorial processes. Attendees expressed the need for similar workshops in the future.

Scoping Review Epilepsy: Last 30 Years in Africa

The scoping review process has so far identified over 4,000 relevant abstracts for evaluation by May of 2019, and these were to be evaluated by eight researchers. Duplicates were removed and most investigators began an evaluation of the abstracts with input onto a REDcap database by September 2019. A total of 698 records are currently archived.

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

Ongoing Projects

The Task Force has two main projects conducted by the group:

1. *Project of CPG for Psychogenic Nonepileptic Seizures in Children and Adolescents: Current State and Future Directions*

After the meeting in Vienna, the task force members delineated the rationale and PICO questions for the CPG. In May 2019, the ILAE

Guideline Committee approved the CPG for Psychogenic Nonepileptic Seizures in Children and Adolescents, with suggestions regarding the PICO questions.

As suggested by the Guidelines TF, a methodologist was invited to take part in both projects. Professor Wang Pang – a psychiatrist and epidemiologist from the University of São Paulo, São Paulo, BR – accepted the invitation as part of the working group. He will provide technical support in methodology for both projects with no fees.

The TF invited experts (Drs. Sigita Plyoplis, Charlotte Rask, Isobel Heyman, and Julie Doss) in the field of Psychogenic Nonepileptic Seizures in Children as part of the working group.

During a four-hour meeting in Bangkok, the task force discussed the next steps for the CPG. Members also discussed the descriptors (MESH terms) and determined the databases for search and the completion and registration of the PROSPERO protocol.

Nathalie Jetté was contacted during the meeting and later reviewed the protocol before registration. A librarian with expertise in systematic reviews (Samantha Walsh), suggested by Dr. Nathalie Jetté, is currently assisting the task force with descriptors and duplicates, and will be part of the working group for this project. Two students, one in the UK and one in Sweden, are also helping Dr. Reilly with the search and selection process.

2. *The International Consensus on Psychiatric Conditions in Pediatric Epilepsy*

After the meeting in Vienna, the rationale for the International Consensus on Psychiatric Conditions in Pediatric Epilepsy, composed of 36 pages, was written, reviewed by all members, and submitted to the Executive Committee. The

Pediatrics Commission *(continued)*

Executive Committee approved the document and recognized its importance to the field, since there is little evidence for guidelines. As recommended, during 2019, the task force members structured the methods.

Dr. Nathalie Jetté, representing the Guidelines Committee, and Prof. Mike Kerr (Chair of the Psychiatry Commission) suggested the Delphi method and the task force described how to use a modified version of the Delphi method for this project, and resubmitted it to the ILAE Guidelines Committee for approval. In November 2019, the TF received a formal output on this project. During our four-hour meeting in Baltimore, Dr. Nathalie Jetté and the TF members reviewed the final details of this proposal. The TF delineated the topics that will be addressed in the Consensus. A group of experts in the field was determined and will be invited to work with the task force.

The task force worked both online and onsite to approve their two main projects, responding to all queries and searching for experts when requested, including a methodologist and a librarian at no cost to the ILAE.

Other Projects

In addition, during these two meetings, the TF members discussed other projects of interest. A preliminary draft of a Survey for Psychogenic Nonepileptic Seizures in Children and Adolescents, written by the Co-chairs was presented and discussed by the task force. We will submit a draft with the suggestions and comments to all members of the task force who could not join this meeting. Markus Reuber, Chair of the Psychogenic Nonepileptic Seizures Task Force, will be contacted as a collaborator and contributor for this project. The task force recognizes that there are many ongoing surveys; however, they consider this survey to be a necessary aspect of our work that is associated with the guidelines that we will implement.

In this project, a post-graduate student from the University of São Paulo with expertise in medical research will take

part and assist the task force in organizing and gathering all data. The decision was made to include a post-graduate student since the current project cannot interfere with the two main projects.

Task Force meetings and educational activities

Task Force meetings

The task force had two four-hour meetings in 2019, as will be described. These meetings were not included in the budget for the Commission of Psychiatry and Pediatrics. The continuous work of the TF members and their presence during our meetings was done with their resources.

- 33rd International Epilepsy Congress (Bangkok, June 24th, 2019) – four-hour meeting. Attendees: Profs. Choong Yi Fong, Colin Reilly, Elaine Wirrell, Kette Valente, Mike Kerr, Stephane Auvin, Symon Kairuki. Colin Reilly and Kette Valente co-chaired the meeting.
- AES annual meeting (Baltimore December 9th, 2019) – four-hour meeting. Attendees: Profs. Kette Valente, Marco Mula, MaryLou Smith, Stephane Auvin. Prof. Nathalie Jetté also attended this meeting. Stephane Auvin and Kette Valente co-chaired the meeting.

During these meetings, as described in items 1 and 2, the TF members discussed barriers and strategies to accomplish our projects.

Educational Events

The Task Force of Pediatric Psychiatric Issues participated in the Educational Symposium "Epilepsy and Psychiatry Throughout Life," held in São Paulo, Brazil, on October 25-26, 2019, by the Psychiatry Commission. The meeting, endorsed by ILAE, had 212 attendees composed of neurologists, child neurologists, psychologists, and neuropsychologists. The Task Force of Pediatric Psychiatric Issues took part, represented by Profs. Stephane Auvin, Kette Valente, Guilherme Polanczyk, and Marco Mula.

Profs. Stephane Auvin, Kette Valente, Guilherme Polanczyk, and Marco Mula participated actively in this educational activity, with lectures and case discussions. Prof. Kette Valente also helped to organize the event.

Pediatrics Commission *(continued)*

International Conferences

The task force has discussed the relevance of our participation in meetings with forums and symposiums. In the past two years, we have submitted proposals addressing comorbidities in pediatric epilepsy.

In Bangkok (2019), members of the task force and the Psychiatry Commission proposed two sessions that were accepted - Childhood Comorbidities: From Mechanism to Management, and Key Neuropsychiatric Issues in Epilepsy, and took part in two round tables about psychiatric disorders in epilepsy.

For Geneva (2020), two sessions were accepted: "What Should Child Neurologists Know When Treating Children with Comorbidities?" and "Diagnosing Neuropsychiatric Conditions in Pediatric Epilepsy."

ILAE Educational Program

The task force is committed to participating in the Educational Program by ILAE. It has been involved in new ILAE e-learning modules focusing on psycho-social issues of epilepsy.

Dissemination of the Pediatric Epilepsy Training (PET) Course

The ILAE Pediatric Commission has continued its implication for the dissemination of the PET course. Jo Wilmshurst has continued the initiation and support of the African-related courses, including serving as faculty lead for some of the South Africa courses, as well as the Namibia one, serving directly on the faculty for the Uganda course, and facilitating [through promotion and funding motivations (ICNA / ILAE)] the Angola course. She also coordinated the framework to prepare for the Zambia and Zimbabwe roll out of establishing faculties – helping recruit planned faculty and getting them through their first PET1 course in preparation (bringing them out to offer the course in Uganda, Namibia and Cape Town). Over the last part of 2019, Jo Wilmshurst supported developing the logistics for the planned French PET roll out.

2019 was a great year for expanding the PET courses at an international level. The course was translated into Portuguese and rolled out in Brazil by the local faculty earlier in the year. In September, the Brazilian faculty



Figure 1: Brazilian faculty running PET course in Luanda, Angola (Kette Valente, Magda Lahorgue Nunes, Leticia Brito Sampaio, Laura Guilhoto, Maria Luiza Manreza, Ana Carolina Coan, and Marilisa Guerreiro).

(faculty leads Marilisa M. Guerreiro and Ana Carolina Coan) travelled to Angola and, with the coordination of local

host Dr. Manuel Leite Cruzeiro, taught the course to 34 local clinicians (32 pediatricians and two neurologists), as well as to two colleagues from Mozambique. Overall, the Brazilian faculty reported that the PET course was able to fill some of the gaps regarding the knowledge of diagnosis and care of children with epileptic seizures and epilepsy. The delegates evaluated the course as good or excellent, and they agreed that it fulfilled or exceeded their expectation. The exposure of the course was viewed to be so useful, especially with the content in the home language, that the Brazilian faculty have been invited to offer the course in Mozambique in 2020. This extension of the PET course to Angola was supported by joint funding from ILAE and the International Child Neurology Association. The same collaboration is planned for the 2020 project.

In addition to support of the Brazil and Angola courses, PET courses were also undertaken across Kenya (faculty leads Pauline Samia and Sam Gwer), Ghana (faculty lead Charles Hammond), Tanzania (faculty lead Edward Kija) (Figures 3 and 4), Namibia (faculty lead Jo Wilmshurst), South Africa (faculty leads Gail Scher, Jo Wilmshurst, Elmarie van Rensburg) and Uganda (faculty leads Angelina Kakooza, Richard Idro) (Figures 5 and 6). The course in Uganda, which was organized by Martin Chebet, took place immediately prior to the African Epilepsy Congress and, as such, was an opportunity for attendees at the AEC to support the Ugandan faculty; namely Helen Cross and Jo Wilmshurst.

Pediatrics Commission *(continued)*

It is estimated that the 2019 course reached some 300 health care practitioners across Africa. The need and demand for the course keeps growing, with plans in 2020 to establish faculties for Zambia and Zimbabwe, as well as translating the course into French to make it possible to develop faculties in the French speaking countries of Africa. Thanks are extended for the ongoing support and collaboration with BPNA, which developed this innovative course. Members of the BPNA have given their time to support the courses as well. For example, Mike Pike joined the faculty for the course in Windhoek, Namibia, and Helen Cross joined for the course in Cape Town.

Report by Stéphane Auvin, Chair, Pediatrics Commission



Figure 4: Helen Cross giving out certificates to delegates who attended the Uganda PET course in Kampala.



Figure 2: Delegates from the Angola PET course, September 2019.



Figure 5: Small group tutorial teaching for the Moshi, Tanzania PET course.



Figure 3: Robert Sebunya teaching the Uganda PET course.



Figure 6: Delegates and faculty for the Moshi, Tanzania PET course.

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)

Aims/Goals of the Commission

The goal of the Psychiatry Commission on 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.

Commission Activities and Accomplishments

Commission meetings:

- The Psychiatry Commission met at The AES annual meeting in Baltimore, December 2019.
- The Task Force on Identification Treatment and Prevention held a one-day meeting in Baltimore in December 2019. This meeting was to work on the protocol and development of a consensus document and clinical practice statements for the treatment of depression in adults with epilepsy.
- The Task Force of Paediatric Psychiatric Issues met at the 33rd International Epilepsy Congress in Bangkok, June 2019.

Educational events:

- The commission held an education symposium entitled, "Epilepsy and psychiatry throughout life" in Sao Paulo Brazil in October 25-26, 2019. The meeting was organised by Professor Kette Valente and Professor Mike Kerr, and endorsed by the ILAE. Sponsorship was provided by ACHE

laboratories and the ILAE. A combination of national and international speakers delivered interactive lectures.

- There were 212 attendees with a waiting list of 35.

Future meetings:

- The Psychiatry Commission intends to hold an executive meeting at the AES Seattle, December 2020.
- The commission hopes to hold a one-day educational event in Curitiba, as a follow up to the highly successful meeting in Sao Paulo, in June 2020 in conjunction with the Brazilian League Against Epilepsy.

Budget

The commission kept within budget for the year 2019-2020.

Commission Contribution to ILAE Conferences

The Psychiatric Commission has contributed to ILAE Conferences in this term with proposals for sessions and forums, as described below:

1. The Psychiatry Commission and the Psychology Task Force held a forum at the 33rd International Epilepsy Congress (Bangkok June 22-26th, 2019) - The International Epilepsy Curriculum: Common errors and their solutions from a psychiatric/ psychological perspective.
2. The Psychiatry Commission held a session on Key Psychiatric Issues in Epilepsy in the 33rd International Epilepsy Congress (Bangkok June 22-26th, 2019).
3. The Psychiatry Commission, represented by the Task Force on Identification, Treatment and Prevention (Prof Marco Mula) and the Psychology Task Force proposed a new session entitled "Screening for and management of suicidal ideation in patients with seizures" for the 14th European

Psychiatry Commission *(continued)*

Conference on Epileptology (Geneva July 5-9th, 2020).

4. Professor Kousuke Kanemoto has submitted a proposal on Psychosis.

- Completed a draft paper on PNES and driving (with input from the ILAE Task Force on Driving Regulations, submitted to Executive Committee for guidance on publication).
- Successfully applied for an ECE Forum for the upcoming conference in Geneva in 2020 on “Social aspects of PNES”.

Task Force progress

The **Task Force on Identification Treatment and Prevention**, chaired by Marco Mula, is working on the development of clinical practice statements for the treatment of depression in adults with epilepsy. The task force has conducted a systematic review of the literature, which will be updated until the document is finalized, and is working on a systematic appraisal of current guidelines of treatment outside epilepsy, in order to adapt them to the needs of people with epilepsy following the ADAPTE process. The document will be finalized in 2020.

The **Intellectual Disability Task Force**, chaired by Christian Brandt, held a session on epilepsy and ID at the IEC in Bangkok, with around 200 participants, and contributed to a Symposium at IEC with the Psychology Task Force on educational issues. The task force continues to develop a protocol on rescue medication. A new initiative working with the recently formed AAN section on IDD aims at developing joint guidelines on management of people with an intellectual disability. The draft protocol has been submitted to the Guidelines Commission.

The **Psychogenic Nonepileptic Seizure Task Force**, chaired by Markus Reuber, has:

- Updated an E-brain Module on “Dissociative (psychogenic nonepileptic) seizures” and contributed to one of the new ILAE e-learning modules focusing primarily on status epilepticus.
- Published a rebuttal to CA Carlson’s paper about PNES published in the Journal of Neurology and Psychiatric Disorders.
- Completed an international survey of the use of suggestion techniques in the diagnosis of patients with PNES (data analysis under way).
- Completed a paper about the aetiology of PNES for the “Seminars” series in Epileptic Disorders

Planned activities that are pending:

- Production of a position paper on diagnostic procedures for PNES (taking account of analyses of survey).
- Proposal for a new PNES label and nosology (the PNES Task Force has submitted a funding request for a structured plan for a two-stage international consultation with a qualitative analysis of the findings of the first survey to the Executive Committee for consideration in the 2020 budget planning).

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.

Work Plans: The task force has developed proposals on two work plans:

1. 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 Guidelines Task Force of the ILAE.
2. 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 Guidelines Task Force of the ILAE.

ILAE Meetings: In addition, the Task Force of Paediatric Psychiatric Issues has contributed to the scientific program of the 14th European Conference on Epileptology (Geneva July 5-9th, 2020) with two proposals accepted.

Psychiatry Commission *(continued)*

The Task Force of Paediatric Psychiatric Issues has also submitted two session proposals to the 34th International Epilepsy Congress (Paris August 28th – September 1st, 2021).

ILAE E-learning: The Task Force of Paediatric Psychiatric Issues contributed in two modules of the ILAE E-learning – Psychosocial Issues in Juvenile Myoclonic Epilepsy and Psychosocial Issues in Neurocysticercosis.

Shared project with Psychology Task force of Medical Therapies Commission:

We are working with the Psychology Task Force in developing a web page on Medical Health Care resources.

Summary

The year 2019-2020 has led to:

1. The development of a work plan from the commission focusing on standards and guidelines by the task forces;
2. The establishment of two liaisons with the Pediatric Commission and the Psychological Therapies Task Force;
3. Contribution to the scientific program of the ILAE Congress in Bangkok;
4. A major multinational Latin America-based congress on psychiatry and epilepsy.

Recommendations for Future Work

Our commission is focused on the completion of ongoing work. In addition to this, we hope that new initiatives such as the guidance on PNES label and nosology will be adopted and funded within the work program.

We seek to strengthen our relationship with other commissions.

Report by Professor Mike Kerr, commission members and task force leads

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

Epilepsy Surgery Developing World

Mario Alonso (Mexico), Chair
Jorge Burneo (Canada)
Sarat Chandra (India)
Katia Lin (Brazil)
Guoming Luan (China)
Andrew McEvoy (UK)
Jo Wilmshurst (South Africa)
Farrah Mateen (USA)

Epilepsy Surgery Education

Stephan Schuele (USA), Chair
Fernando Cendes (Brazil)
Rei Enatsu (Japan)
Stefano Francione (Italy)
Enrico Ghizoni (Brazil)
Moosa Naduvil (USA)
Cigdem Özkara (Turkey)
Karl Rössler (Germany)

Epilepsy Surgery Outcomes

Lara Jehi (USA), Chair
Fabrice Bartolomei (France)
Robyn Busch (USA)
Mark Keezer (Canada)
Guoming Luan (China)
Kristina Malmgren (Sweden)
Americo Sakamoto (Brazil)
Laura Tassi (Italy)
Jose Tellez-Zenteno (Canada)

Evidence-based Practice of Epilepsy Surgery

Dario Englot (USA), Chair
Kees Braun (Netherlands)
Ed Faught (USA)
Dan Friedman (USA)
Nathalie Jette (USA)
John Rolston (USA)
Felix Rosenow (Germany)
Michael Sperling (USA)
Sumeet Vadera (USA)
Satsuki Watanabe (Canada)
Lily Wong-Kiesel (USA)

Pediatric Epilepsy Surgery

Eliseu Paglioli (Brazil), Chair
William Gaillard (USA), Past-chair
Thomas Czech (Austria)
Bertrand Devaux (France)
Martha Feucht (Austria)
Wirgina Maixner (Australia)
Andre Palmini (Brazil)
Karl Rössler (Germany)
Bertil Rydenhag (Sweden)
Howard Weiner (USA)
Natrutjee Wiwattanadittakun (Thailand)

Working Group Meeting: AES meeting, Baltimore, December 7, 2019

Opening remarks: high-level highlights of progress made since last year. Mission of the commission was re-emphasized: to advance the surgical care of patients with drug-resistant epilepsy.

Discussions throughout the day covered the different projects now underway:

1. **Memory Assessment Clinics Self-Rating Scale (MAC-S) validation study in adult epilepsy.**
Presentation by Robyn Busch.
 - a. **Rationale:** Existing memory assessment tools

Surgical Therapies Commission *(continued)*

- through formal neuropsychological testing are time consuming and do not always correlate with a patient's subjective assessment of function (before or after epilepsy surgery). A patient-reported outcome measure evaluating memory function can be a very useful tool for clinical care and for research.
- b. **Goal:** Develop and validate an abbreviated measure of MAC-S (measure of subjective assessment of memory function) for epilepsy to improve feasibility of future research.
 - c. **Data:** CCF using MAC-S clinically since 1989 (1,333 patients).
 - d. **Aims:** Examine structure of MAC-S in epilepsy using a large sample and up-to-date psychometric evaluation techniques. Identify an abbreviated measure to improve feasibility of future research. Externally validate at US partner sites. Translate and validate measure at international partner sites. Conduct a large-scale, international study using shortened version along with ESSQ in patients who have undergone epilepsy surgery.
 - e. **Progress:**
 - i. Study sites identified so far: Cleveland Clinic (Busch, Jehi); New York University (Friedman, Barr); Northwestern University (Schuele, Sieg); Istanbul University (Yagci, Ozkara); University Federal de Santa Catarina (Lin); Sahlgrenska University Hospital (Malmgren).
 - ii. English abbreviated version is already developed from Cleveland Clinic patients (N=1,333). Measure was shortened from 49 items down to 23.
 - f. **Next steps proposed by study team:**
 - i. Publish internal validation data in a neuropsychology journal.
 - ii. US sites to start administering MAC-S with epilepsy surgery neuropsychological evaluations for external validation project.
 - iii. Northwestern – DUA executed and IRB approved.
 - iv. NYU – DUA drafted; CCF edits under review by NYU.
 - v. MAC-S and neuropsychological data entered into REDCap database hosted by CCF.
 - vi. Analyze and publish external validation data.
 - vii. Translate validated measure into Turkish, Portuguese, Swedish, etc.
 - viii. Validation studies in other languages/countries.
 - ix. Large scale international study administering MAC-S and ESSQ.
 - g. **Additional next steps proposed by Commission during meeting:**
 - i. Translate also to French and German.
 - ii. Explore alternative statistical methods for factor analysis and shortening of scale to its critical components (proposed by Mark Keezer)
 - iii. Several commission members expressed interest in joining this project at the external validation stage, including Americo Sakamoto and Bertrand Devaux.
2. **Addressing the epilepsy surgery treatment gap:**
 - a. New project idea presented by Americo Sakamoto.
 - b. **Rationale:** despite clear superiority data, epilepsy surgery continues to be underutilized. A better understanding of this underutilization is needed.
 - c. No clear study design exists at this point. The discussion is early, geared mainly towards judging interest of the group.
 - d. The group discussed at length that the problem is multifaceted and complex. However, it is an important issue that clearly falls within the mission of the Commission. Group expressed interest to pursue.
 - e. **Next steps:**
 - i. Define the goal of the project:
 1. Obtain data to objectively quantify the

Surgical Therapies Commission *(continued)*

- surgery treatment gap? (This would require a rigorous survey design and support lobbying for resources to reduce treatment gap).
 2. Discuss strategies to reduce treatment gap? (One potential approach may be to publish a white paper with proposals/examples of success in addressing various bottlenecks of care. Examples may be the Ontario Comprehensive Epilepsy Care program (mentioned by Mark Keezer) in health policy framework; direct to patient education (Dario Englot) in fee-for-service consumer-driven health markets like the US and in other referral base driven programs in Europe (Bertil Rydenhaag); reimbursement driven patterns of care (VNS utilization change with change in CMS reimbursement in the US); Centers of Excellence approach (e.g.: UK experience); etc.).
 3. Develop a stepwise plan for the project and define team members.
 4. Americo Sakamoto will follow up with Lara Jehi in two months with progress.
3. **Survey about current practices regarding epilepsy surgery outcomes captured in clinical practice** (Presented by Jose Tellez):
 - a. **Rationale:** a comprehensive assessment of the current outcome practice assessment practices will be helpful to define existing infrastructure for measuring variation in care and treatment outcomes internationally, to ultimately help drive resources and support to programs.
 - b. The **objectives** for the overall project are:
 - i. To identify the outcomes ascertained in epilepsy centers after epilepsy surgery.
 - ii. To identify the methods used to ascertain these outcomes after epilepsy surgery.
 - c. **Survey design** and content was discussed. Meeting members emphasized need for a succinct survey to optimize completion.
 - d. Target **survey recipients:** major epilepsy surgery programs (project team will coordinate with L. Jehi, who will share a recently compiled such list, Bertil Rydenhaag, who will connect with E-Pilepsy team, and Guoming Luan, who can provide a list of 15 centers in China).
 - e. **Suggestions** from meeting attendees:
 - i. Shorten survey. Target completion time should be ten minutes or less.
 - ii. Validate survey with commission members.
 - iii. Include pediatric and adult programs.
 - iv. Ask about when did programs start collecting outcomes systematically.
 - v. Clarify breadth and depth of outcome collection (seizure outcomes only or also include cognitive, psychiatric, etc.? Routine inclusion in templated clinic notes? Systematic cataloguing into a database? Regular analysis for clinical care? Research only?).
 - vi. Include educational and vocational outcomes.
 - f. Current **team members:** Jose Tellez, Nathalie Jette. Team members added in meeting: Mark Keezer and Martha Feucht.
 - g. **Next steps:** revise survey and circulate to commission leadership for input.
 4. **Neurostimulation in Drug-Resistant Epilepsy systematic review** (Dario Englot and Mark Keezer):
 - a. **Objective:** provide practical and accessible guidance on the use of three available neuromodulation options (RNS, VNS, DBS).
 - b. **Method:** systematic review to include RCT and observational large studies.
 - c. Team reviewed progress so far:
 - i. Systematic review: close to completion
 - ii. Develop professional consensus (using Delphi method): planned as next step.

Surgical Therapies Commission *(continued)*

- d. Suggestions during meeting:
 - i. Mike Sperling: compare outcomes and complications between RCTs/post-marketing studies done under FDA regulation vs open-label observational series with no oversight; compare quality across studies and assess for biases in reporting.
 - ii. Several members: highlight value in developing consensus over areas where new data are needed. Opportunity for collaboration with other societies e.g., AAN, NAEC.
5. **Pediatric epilepsy surgery outcome scale development** (Helen Cross and Andre Palmini):
 - a. Group reviewed discussions on this topic from the Pediatric Epilepsy Surgery taskforce led by Dr. Cross.
 - b. **Rationale:** Surgical Therapies Commission recognizes the limitation of existing outcome assessment scales exclusively focused on seizure burden in capturing full scope of benefits of epilepsy surgery, particularly in pediatric (and adult) patient population with catastrophic or multifocal epilepsy. A scale that evaluates burden or severity of epilepsy beyond seizures (to potentially also include functional measures, comorbidities, medication side effects, QOL, etc.) is needed.
 - c. Existing efforts to develop a scale with these goals (measure seizures AND function) were discussed, particularly by the Porto Allegre team, led by Andre Palmini, to illustrate and emphasize the importance of this initiative.
 - d. Consensus on need for such a scale was evident and reaffirmed.
 - e. Scope of such a scale was discussed. Multiple members of the commission highlighted that an epilepsy burden scale that is usable throughout the patient treatment trajectory (medical through surgical) can help in providing continuity of disease assessment. However, the team ultimately decided to restrict the scale development to epilepsy surgery at this point (since it is being developed under the umbrella of the Surgical therapies Commission and Pediatric Epilepsy Surgery Task Force) but liaise with other ILAE bodies that may be interested or engaged already in similar efforts for medical epilepsy treatment.
6. **Survey of training resources for trainees from resource poor countries** (Jorge Burneo):
 - a. **Rationale:** one component of a larger strategy to increase access to epilepsy surgery in resource-poor countries is to build a dedicated specialized workforce. A starting point is to survey what is available.
 - b. Jorge Burneo reviewed results of his outreach so far.
 - c. Team discussed path forward and had several suggestions:
 - i. Expand definition of epilepsy training beyond formal clinical fellowship to also include one-year (or longer) clinical research epilepsy fellowships, and neurology residency training with a dedicated focus on epilepsy (to be better defined by Jo Wilmhurst).
 - ii. Expand data collected to also include source of funding, eligibility requirements, duration of programs, and other variables.
 - d. **Next steps:**
 - i. Jorge Burneo is to develop a survey draft and circulate to the commission leadership and members of the Taskforce for Resource Poor Countries for feedback.
 - ii. He will obtain a list of survey recipients from Lara Jehi (may use list developed for Project 3 once finalized).
- f. **Next steps:** Working group to include members from Pediatric Surgery Task Force and Surgical Commission will be developed to pursue this project further.

Surgical Therapies Commission *(continued)*

7. **Comparative Effectiveness of SEEG and SDE study** (Lara Jehi):
- a. *Rationale:* in absence of RCT, the community needs a rigorous comparative effectiveness study comparing outcomes and complications across the two main invasive EEG modalities currently in use.
 - b. Team development was reviewed (currently ten epilepsy surgery programs, seven countries, three continents).
 - c. Data collection progress was reviewed (data available for analysis on 1,217 patients now; expected to expand to 2,554 patients once data collection is completed in NYU and DUA finalized with Utrecht).
 - d. Discussion centered on prioritizing research questions. Team decided to start with localization yield/subsequent resection, seizure outcomes, and complications (although the complications will not be available on everyone).
 - e. Subsequent more detailed analyses were proposed. Examples included comparative effectiveness re: precision outcomes (successful functional mapping, successful targeting of lesions of interest); healthcare delivery outcomes (cost), and others. These would require additional data collection such as more detailed surgical characterization (frameless vs frame; robot vs no robot, etc.). Team felt that these sub-analyses should be performed on subgroups, rather than requiring additional data collection on all 2,554 patients.
 - f. Several commission members expressed interest in joining the project, which was encouraged as several additional research questions will be asked of this large dataset.
 - g. *Next steps:*
 - i. Complete data collection.
 - ii. Arrangement with statistician to start primary analysis on January 15.
 - iii. Sites interested in participating will contact Lara Jehi to start the process (DUA and data collection).

8. Subsequent to individual project presentations, core commission members and task force chairs met to assess the overall progress within the Commission. Impression was that of constructive progress. Opportunities for additional projects were identified, including one for “direct to patient education” efforts to raise awareness on epilepsy surgery (these may leverage existing efforts of other organizations and require building partnerships with EFA, EPICARE, and others) (Stephan Scheule and Dario Englot). Another idea was consideration for an Epilepsy Surgery Consortium that can coordinate and leverage participation of commission sites and partners for comparative effectiveness epilepsy research, and other large-scale projects such as those currently underway within the commission, and others that may address emerging therapies. These exploratory ideas will be brought for discussion with the larger commission group and with the ILAE leadership as they continue to evolve.

Report by Lara Jehi

Young Epilepsy Section (YES)



Marian Galovic

Chair

Marian Galovic (UK)

Members

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

Regional Representatives

Naluca Mwendaweli (Zambia), Africa
Mohmad Farooq Shaikh (Malaysia), Asia/Oceania
Reem Alyoubi (Saudi Arabia), Eastern Mediterranean
Caroline Neuray (Austria), Europe
Johann Sebastian Ortiz De la Rosa (Colombia), Latin America
Taylor Abel (USA), North America

Task Force Leaders

Advocacy – Manuela Ochoa-Urrea (Colombia)
Education – Christoph Schoene-Bake (Germany)
Career Development – Katja Kobow (Germany)
Research – Christos Lisgaras (Greece)
Publications – Nadia Khan (USA)
Opportunities – Victoria Gruber (Austria)
Conference – Caroline Neuray (Austria)
Visiting Fellowships – Mirja Steinbrenner (Germany)
Communication – Neha Kaul (Australia)
Interactive Media – Patricia Saletti (USA)

Aims/Goals of the Commission

At the 2019 International Epilepsy Congress (IEC) in Bangkok, the Young Epilepsy Section (YES) of the International League Against Epilepsy (ILAE; ILAE-YES) celebrated its first year of operation with chocolate cake and vision. Specifically, the milestone was a time to formally reflect on the mission and organizational structure of ILAE-YES moving forward, as well as a time to recognize our many achievements to date.

The Young Epilepsy Section (YES) of the ILAE was founded in 2018 with the aim of improving the professional development of young people in epilepsy, and to deepen the participation of young people in the ILAE for their mutual benefit. ILAE-YES is a worldwide organization of young people in the early stages of a career focused on the care of people with epilepsy, and/or epilepsy research; this includes clinical and basic scientists, nurses, physicians, students, psychologists, pharmacologists, physicists, mathematicians, and allied health professionals.

Commission Activities and Accomplishments



Contributors

Within its first 18 months, ILAE-YES attracted an active group of more than 400 young people involved in epilepsy care and research the world over. Thanks to our grassroots organizational structure, our collaborators directly contribute to our task forces and regional programs via our online internal communication platform on Slack. Contributor numbers continue to climb as a result of our prominent ILAE-YES booths at the IEC and all ILAE regional congresses.

Governance

Regular Leadership Team meetings, chaired by members of the Board, are central to the internal workings of YES. These bi-weekly Zoom conferences are useful to discuss projects, allocate tasks, and distribute responsibilities. In the latter part of 2019, these meetings were opened up to all contributors to ILAE-YES, both to improve the transparency of our operation, and so that our programs and task forces may benefit from the expertise and enthusiasm of our collaborators.

At our General Assembly Meeting in Bangkok, the ILAE-YES Terms of Reference were updated and approved. In particular, the responsibilities of the Leadership Team were formalized, a transparent process for nominations of YES representatives for external (i.e., ILAE) committees and task

Young Epilepsy Section *(continued)*

forces was developed, the positions of National Liaisons were defined, and guidelines for the approval of national YES chapters were proposed. At this meeting, the Leadership Team was re-elected, and the structure of the task forces re-defined.

Activities Overview

YES received an annual budget through the ILAE Next Generation Task Force. This enabled us to efficiently and independently carry out activities throughout the year for the benefit of young people involved in epilepsy care or research. The majority of these funds flowed into projects at ILAE conferences, specifically targeting young attendees (networking and social activities, scientific brainstorming events, career development sessions) and into numerous travel bursaries to assist our most active YES contributors in attending the IEC and ILAE regional congresses.

Regional Overview

ILAE-YES regional representatives have organized meetings at all regional ILAE congresses to date, to introduce YES and its mission to their peers, and to develop organizational structures for YES in their region. To this end, many regional representatives have appointed national liaisons to YES, with an aim of appointing a liaison for each country within their region so that there is a direct link between YES and each chapter of the ILAE worldwide. There is also a handful of YES National Chapters established in countries with a particular need for a dedicated junior branch of the local ILAE chapter. The diversity of needs amongst the global ILAE regions is recognized, however, with national liaisons planned to span several small countries in Africa, or else numerous national liaisons to cover the globe's more populous countries such as China.

Reflecting the great support that ILAE-YES enjoys from the ILAE Executive Committee, our members have been appointed to the Scientific Organizing Committees of each regional congress and the Paris IEC, to ensure that the needs and expectations of junior conference participants are addressed. Two members from YES Africa have also joined the ILAE Task Force on Research Advocacy and Priorities.

Task Force Overview

To facilitate and support internal communication among ILAE-YES members, the *YES Communications Task Force* created an online sign-up sheet and mailing list linked to the YES website (www.ilae.org/yes) in accordance with international privacy protection standards, publish the regular YES newsletters, created a YES branding profile, and undertook a successful trial of creating five infographics of key ILAE position papers in collaboration with the ILAE Communications and Social Media Task Force. In conjunction with *Epileptic Disorders*, the YES Communications TF (task force) facilitated the posting of short clinical cases on social media to enrich online education opportunities.

In close collaboration, the *Interactive Media Task Force* curates our social media accounts on Facebook and Twitter in multiple languages, with content so far available in Arabic, Spanish, Japanese, German, Portuguese, and French.

The *Advocacy Task Force* works to increase YES engagement in low resource regions and has established relationships with key epilepsy advocacy associations, such as the IBE. The Advocacy TF leads YES celebrations for Purple Day and International Epilepsy Month via social media, in addition to providing resources for YES members to deploy at their local hospital or community.

The *Education and Career Development Task Forces* successfully developed a Peer2Peer (P2P) Mentoring Program, which connects experienced clinical fellows/researchers with younger early career colleagues (e.g., resident, PhD student, etc.) to act as mentors. The trial program at Bangkok saw 13 mentees selected and matched with mentors from the YES community and beyond, with encouraging feedback. This TF was also heavily involved in development of the roadmap published in *Epileptic Disorders* in 2019 as part of the ILAE Epilepsy Education Task Force's development of a competency-based curriculum for epileptology. Members from the YES Education Task Force together with senior tutors from the ILAE Education Task Force prepared modules and cases for this innovative

Young Epilepsy Section *(continued)*

curriculum. A *Visiting Fellowships TF* is currently piloting a short-term intra-regional fellowship program in Europe, with the aim of ultimately rolling it out worldwide.

ILAE-YES has continued to have a strong presence at the IEC and all the regional epilepsy congresses, thanks to efficient and fruitful knowledge-sharing facilitated by the *Conference TF* in conjunction with the YES regional representatives. This is underscored by the work of the *Research and Translation TF*, which has contributed to several conference activities such as career development forums, translational science brainstorming sessions, poster and presented prizes, and many dozen poster tours covering every topic category and led by members of the YES team. The Research and Translation TF also enjoys a productive collaboration with the *Young Neurobiologists Task Force (YNTF)* of the Neurobiology Commission, initiating joint activities on basic science and with our members invited to contribute to ILAE's Research Advocacy and Priorities Task Force. The Research and Translational TF have also joined efforts with the ILAE Wikipedia Epilepsy Initiative to collaborate on epilepsy-related entries and to this end, nine articles written by YES members have been published after review from the YES editorial team, a task now absorbed by the new Publications TF. The Research and Translational Task Force also commenced work curating a centralized database for training opportunities, courses, and fellowships; a task now taken up by a dedicated *Opportunities TF*.

Recommendations for Future Work

Despite the rapid growth of YES during its first years, there are several areas that require increased focus over the upcoming year. In particular, we will seek to increase the number and diversity of active contributors to YES; Regions particularly requiring growth are Africa, mainland Asia, and North America. To achieve this aim, we will reinforce the position of Regional Representatives, by expanding the nomination of National Liaisons targeted to these underrepresented regions, as well as the creation of National Chapters.

Much of our initial work so far has focused on improving ILAE congresses for younger participants. In the future, we aim to provide useful services throughout the year. This will involve online databases for fellowships, courses and positions, scientific tutorials, infographics, pocket cards, contributions to the education curriculum, etc. Underscoring the significant impact YES has made in its inaugural year, several ILAE committees reached out to YES to provide input and nominate representatives. We aim to expand our involvement within the ILAE to better represent the concerns of young people within the League. We have a clear target to involve YES representatives in all regional commissions, conference organizing committees, the League's Executive Committee, and several relevant task forces, and are on track to achieving this.

Report by Genevieve Rayner, Marian Galovic

Chapters

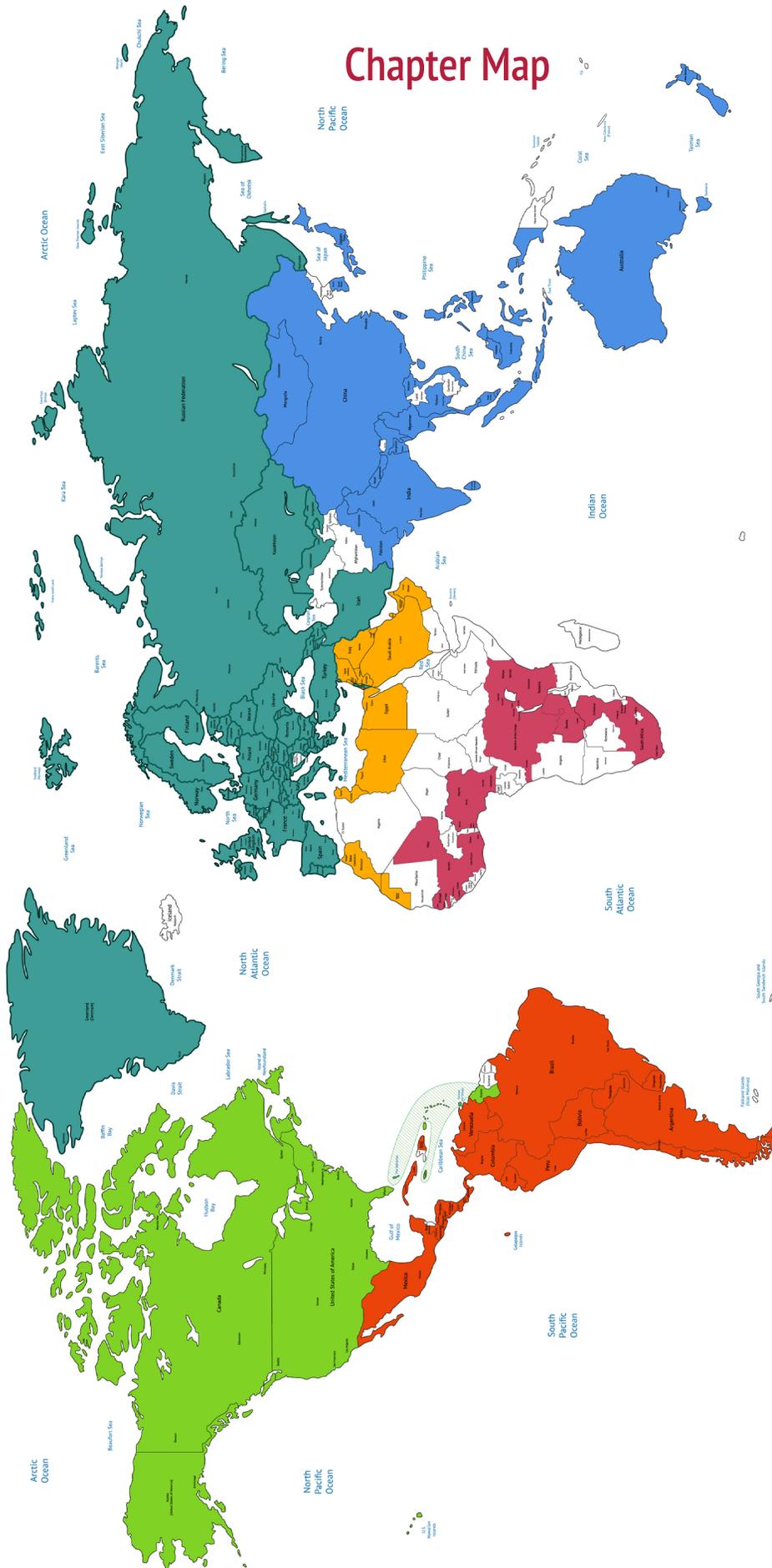
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Taiwan
Tanzania
Thailand
Tunisia
Turkey
Uganda
Ukraine
United Arab Emirates
United Kingdom
United States of America
Uruguay
Uzbekistan
Venezuela
Vietnam
Zambia
Zimbabwe

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

Chapter Map



ILAE-Asia and Oceania

ILAE-Eastern Mediterranean

ILAE-Africa

ILAE-Europe

ILAE-Latin America

ILAE-North America

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

CONSTITUTION *(continued)*

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 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:
 - A. The President, Vice President, Secretary-General, Treasurer, and the Immediate Past President, and the Chair of each of the recognized ILAE regions as voting members. Within the executive committee, Regional Chairs will work on behalf of, and in the best interests of the ILAE globally.
 - B. The President, Secretary-General and Treasurer of the International Bureau for Epilepsy, (hereinafter called the "IBE"), as ex-officio, non-voting members.
 - C. The Editor-in-Chief of *Epilepsia* as a non-voting member, appointed by the voting members of the Executive Committee.
3. The Management Committee:
 - A. Shall consist of the President, Vice President, Secretary-General, Treasurer, and Immediate Past President.
 - B. The Management Committee will implement the policies approved by the Executive Committee and govern the League between meetings of the Executive Committee.

CONSTITUTION *(continued)*

- C. The geographic distribution of the elected officers, including the President, shall be restricted as follows: Each of the newly elected Management Committee members must be primary members of different Chapters. Primary membership is defined by the location in which professional activities are performed. No more than two of the newly elected members of the Management Committee shall come from the same region, as defined by the geographic regions recognized by ILAE.
- D. The President shall serve one term. Candidates for the Presidency must have served, or be in the process of serving, at least one term on the Executive Committee either as an elected or ex-officio member. After serving as President, the person shall automatically serve one term as Immediate Past President.
- E. The term of office for any Executive Committee member is four years. The members of the Executive Committee may be re-elected or re-appointed for one additional term to any of these offices. No member of the Executive Committee can serve more than two terms as an elected officer, unless elected as President. No person may occupy a seat on the Executive Committee for a period exceeding a maximum of sixteen years.
- F. If the current President cannot fulfill the full term of office, a new President will be selected in accordance with the Bylaws. Should any vacancy in the Executive Committee occur it shall be addressed by the Executive Committee subject to ratification by the General Assembly.
- G. The President shall appoint an independent Elections Commission. The Elections Commission shall be chaired by the Immediate Past President. It will include one person from each of the recognized ILAE regions and the Immediate Past Chair of the Elections Commission. The Executive Committee shall not interfere with the business of the Elections Commission. The Commission is to conduct the elections and establish appropriate procedures as described in the Bylaws and that are not in conflict with the constitution.
- H. The Executive Committee may hold meetings at any time or in any place which may be convenient to its members; it may conduct its business also by other appropriate means of communication. The business decisions of the Executive Committee once taken become effective, will be recorded in minutes and the minutes will be approved at the next meeting.
- I. Two-thirds of the voting members of the Executive Committee constitute a quorum. Decisions are made by a majority of the voting members attending. In the event of a tie, the President has a deciding vote.
- J. The Executive Committee shall have the power to formulate at any time 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.
- K. The Executive Committee shall approve the annual budget of the ILAE and shall set the dues to be paid by the Chapters.

Article IX – The General Assembly

1. The General Assembly consists of all approved Chapters of the ILAE.
2. Regular meetings of the General Assembly shall be convened during each International Congress of the ILAE. Participants shall consist of one delegate from each Chapter who carries the total number of votes of that chapter.

CONSTITUTION *(continued)*

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 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

CONSTITUTION *(continued)*

commissions and task forces, except the Elections Commission.

2. No expenses shall be incurred by a Commission or Task Force on behalf of the ILAE without the consent of the Executive Committee.
3. Annual budgets and financial reports of the Commissions and Task Forces must be approved by the Executive Committee.
4. Regional Commissions must have written rules of procedure that are in agreement with the League's Constitution and Bylaws. A copy must be kept in the League's Headquarters Office. Any changes in these rules must be submitted to the Executive Committee for ratification.

Article XIII – International Bureau for Epilepsy

1. A privileged relationship exists between ILAE and IBE as partners for addressing respectively the professional and social aspects of the epilepsies.
2. ILAE and IBE will establish appropriate administrative structures that will facilitate the accomplishment of mutual objectives.

Article XIV – Amendments

1. The present Constitution may be amended by a two-thirds vote of those attending the meeting of the General Assembly.
2. Amendments may be initiated by the Executive Committee, or by Chapters whose total votes correspond to a minimum of twenty-five percent of the votes of the General Assembly. Such amendments must be submitted to the Secretary-General at least ninety days before the next meeting of the General Assembly, and due notice of such amendments shall be given to all Chapters by the Secretary-General at least sixty days before the meeting of the General Assembly.

Article XV – Dissolution or Merger

1. The ILAE may be dissolved or merged with another body having similar objectives on proposal of the Executive Committee, ratified by two-thirds of the 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, June 2019, January 2020, April 2020*

**Some items are pending ratification of constitutional amendments by the ILAE General Assembly*

The Executive Committee is empowered by the Constitution (Article VIII8) 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 Committee shall be chaired by the Immediate Past President of the League. The remainder of the Commission will include the immediate Past Chair and one representative appointed by the President from each of the League's geographical regions.
2. For each phase of the election, the Elections Committee shall ascertain if candidates are available and willing to serve. Candidates will provide the Elections Committee with appropriate background information on their candidacy. This information will be sent to each Chapter and publicized in the ILAE Website. Each candidate running for election must have the support of his or her respective chapter, but not necessarily nomination (when applicable) by his or her respective chapter.
3. Each Chapter has from 1-6 votes. The number of votes accorded to each Chapter shall depend on the number of professional dues paying members

in that Chapter according to the most recent statement provided by the Chapter. The number of votes shall be determined by a sliding scale as follows:

- up to 50 members: 1 vote
- 51 – 150 members: 2 votes
- 151 – 350 members: 3 votes
- 351 – 750 members: 4 votes
- 751 – 1500 members: 5 votes
- above 1500 members: 6 votes

Chapters that do not collect dues shall have one vote.

4. All votes are secret. To ensure secrecy in all voting processes, the Election Committee shall appoint an independent third party, who shall be responsible for receiving the chapters' votes. The third party will inform chapters by email or fax within 72 hours that their vote was received, and will transmit the counts of votes to the Election Committee. The number of votes received by each candidate at each election stage will be disclosed publicly at the completion of all election stages, including any run-off election.
5. For the election of the President, the Elections Committee shall submit to the Chapters a list of persons fulfilling the requirements of the Constitution (Article VIII), who are available and willing to serve. Each candidate running for election must have the support of his or her respective chapter. The Elections Committee will ask each Chapter to vote for one of them by email or fax. If one of the candidates receives more than fifty percent of all possible weighted votes, this candidate shall be elected. If this is not the case, a 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, i.e. Secretary-General, Treasurer and Vice-President.
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 boards as follows:
 - A. There should be eight voting members in each regional board. 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 board 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 board 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 board 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 board. 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 board. These appointed members should have served no more than 1 previous voting term.
- G. ILAE-North America 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 ILAE-North America, 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 ILAE-North America Chair. The role of the Regional Selection Committee is to create a Regional board 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 board 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 ILAE-North America Regional 5 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 board. 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 ILAE-North America 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 ILAE-North America:
 - 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 ILAE-North America 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 regional board and for the other members of the board. 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 regional board are decided by the board members based on their rules of procedure. It is recommended that regional board have education and information officers, and liaisons to global outreach and to neurobiology.
- iv. The election of the new members of ILAE-North America will be completed at the same time as the other regional boards.

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 Committee;

- G. Promote active participation in ILAE activities, and report the activities of the executive Committee and ILAE to the chapters through email broadcasts, the ILAE Website, Epigraph and other publications;
 - H. Serve as an ILAE representative on the IBE Executive committee and maintain liaisons with other related organizations;
 - I. Monitor the activities, programs, and developments of ILAE, supporting and promoting policies and programs adopted by the chapters, Executive Committee, and Commissions.
 - J. Provide the leadership for monitoring the ILAE strategic plan;
 - K. Recommend initiatives, research, and special assistance whenever necessary for Executive committee approval;
 - L. Assume a key role in the orientation and transition of the President-elect;
 - M. Identify, recruit and cultivate future leaders of the ILAE;
 - N. Assume other duties and responsibilities as may be assigned by the Executive Committee.
2. The Secretary-General ensures that records are maintained of all General Assembly and Executive Committee Meetings, and encourages chapter development. Specifically, the Secretary General shall:
 - A. Serve as a member of the Executive and Management Committee;
 - B. Oversee the maintenance of the official records of ILAE including (i) minutes of regularly called meetings of the General Assembly and Executive Committee; (ii) affiliated chapters in good standing; (iii) official correspondence to and from ILAE and other entities;
 - C. Maintain the Constitution and Bylaws, including responsibility for the process of amending the official documents;
 - D. Give timely notice of all meetings of the General Assembly and Executive Committee;
 - E. Conduct a roll call of the members at the

- meetings of the General Assembly and Executive Committee meetings, assuring that a quorum is present;
- F. Promote chapter development and support activities; review applications and supporting documents for the establishment of new chapters and provide guidance to the Executive Committee regarding the approval process;
 - G. Serve as an ex officio ILAE representative on the IBE Executive Committee;
 - H. Represent ILAE with other associations or entities as assigned by the President or Executive Committee;
 - I. Receive, process and maintain the reports of Commission and Task Forces, submitting such reports to the Publication Task Force for review, with subsequent recommendation to the Executive Committee for approval for submission to Epilepsia, Epilepsia Open or Epileptic Disorders;
 - J. Oversee the publication of the Annual Report;
 - K. Perform such other duties and assume such responsibilities as may be assigned by the President or Executive Committee.
3. The Treasurer ensures the integrity of the fiscal affairs of ILAE. Specifically, the Treasurer shall:
 - A. Serve as a member of the Executive and Management Committee;
 - B. Ensure that the ILAE accounts are maintained according to international accounting standards, assuring the financial integrity of ILAE;
 - C. Exercise prudence in maintaining the assets of ILAE;
 - D. Report on the financial condition of ILAE at the meeting of the General Assembly and the Executive Committee;
 - E. Submit the financial account of ILAE to an annual audit;
 - F. Working with the staff, develop the annual budget for review and approval by the Finance and Executive Committees;
 - G. Monitor the financial performance of ILAE in relation to the annual budget
 - H. Ensure the timely payment of all ILAE financial obligations;
 - I. Oversee financial long-range planning;
 - J. Serve as an ex officio ILAE representative in the IBE Executive Committee;
 - K. Retain authority and responsibility for the financial activity of ILAE when such activities are delegated to staff or contracted with an external entity;
 - L. Perform such other duties and assume such responsibilities as may be assigned by the President or Executive Committee.
4. The Vice-President will:
 - A. Serve as member of the Executive and Management Committee;
 - B. 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 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 Editor(s)-in-Chief of the ILAE Journals shall be appointed by the Executive Committee, serve at its discretion and conduct the day-to-day editorial business of the Journals. It may be appropriate for

the Executive committee to appoint more than one Editor-in-Chief of each Journal. The Editors in Chief of the ILAE Journals shall be represented in the Publications Council. The chair of the Publications Council will be a non-voting ex-officio member of the Executive Committee. The editorial content of the ILAE Journals is the responsibility of the Editor(s)-in-Chief. Specifically, the Editor(s)-in-Chief of each ILAE Journal shall:

- 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;
- Make recommendations to the Executive regarding number and role of Associate Editors and Managing Editor;
- Appoint the associate /editors and the members of the editorial Board, and supervise communication with the Board;
- Call meetings of the Editorial Board as needed;
- Recommend an annual budget for the Journal to the Executive Committee;
- Liaise with the Publisher and oversee compliance with the contract;
- Assists the Treasurer in supervising expenditures for the Journal office;
- Perform other tasks as necessary for the operation of, and maintenance of quality, of the journal.

Article V- ILAE Organizational Entities

1. As per Article XII of the Constitution, organizational entities may be appointed by the President of the ILAE as recommended by the Executive Committee, to carry out specific ILAE activities.
2. The main organizational entities of the League are Councils, Topic-Oriented Commissions, Committees and Task Forces. The roles, responsibilities, composition, terms and reporting structure of these entities are as follows:

A. Councils

- Role and responsibilities: Councils serve as an oversight and coordinating group with a specific purpose for an indefinite period of time, based on functions defined by the League's Mission and Strategic Plan. The council is responsible for long- and short-term planning, for policy review and recommendation to the Executive Committee. Examples of Councils include Education, Publications, Congresses, Global Advocacy.
- Composition and Terms: Councils are standing organizational entities. The Chair is appointed by the ILAE President in consultation with the Executive Committee and serves as an ex-officio member of the Executive Committee. The Chair serves for four years, cannot serve more than one term as Chair, and will have served in the council in the previous term. Members are appointed by the President in consultation with Chair and Executive Committee, and serve for one four-year term, unless appointed as Chair of the Council. To allow for overlap with consecutive Executive Committees, one half of the members are appointed two years after the installation of each Executive Committee. The ILAE President, in consultation with the Council Chair may appoint Task Forces as needed.
- A Management Committee Liaison is appointed by the ILAE President.
- Reporting structure: Councils report directly to the Executive Committee.
- The Publications Council is a special case of this organizational entity, whose composition is influenced by the appointments and terms of contract of the Editors-in-Chief of the League Journals. The Publications Council will

be composed of the Editors-in-Chief of Epilepsia, Epilepsia Open and Epileptic Disorders; the Editor-in-Chief of the Wikipedia-ILAE project; the editor of Epigraph/ILAE Communications; the chair of ILAE Web-Media; the Chair of the Education Council; and a liaison of the Management Committee appointed by the ILAE President. The Chair of the Publications Council is appointed by the ILAE President from among the Council Members in consultation with the Executive Committee. The term of the Chair will be four years plus two years as past chair, and the Chair cannot serve more than one term as Chair. Members who are Editors-in-Chief will serve for the duration of their tenure as Editors-in-Chief. Members who are not Editors-in-Chief will serve for four years and can only serve one term, unless appointed as Chair.

B. *Regional Boards*

- The roles, responsibilities, composition, terms and reporting structure of Regional boards are outlined in Article XI of the bylaws and in the Constitution.

D. *Topic Oriented Commissions*

- **Role and Responsibilities:** These organizational entities examine a specific topic and recommend how the League can help move forward with a global or international perspective; they have clearly identified goals and steps to realize these goals.
- **Composition and Terms:** The term of the Commission is the same as the term of the Executive and shall expire within six months of the end of the term of the Executive Committee to complete unfinished business. The Chair is appointed by the ILAE President in consultation with the Executive Committee. The Past-Chair may remain

as a member of a new Commission.

Commission Members are appointed by the ILAE President in consultation with the Commission Chair and serve for one four-year term, unless appointed as Chair. The ILAE President, in consultation with the Commission Chair may appoint Task Forces as needed. Liaisons to other commissions are encouraged.

- A Management Committee Liaison is appointed by the ILAE President
- **Reporting structure:** Topic Oriented Commissions report directly to the Executive Committee.

E. *Committees*

- **Role and Responsibilities:** These are first level organizational entities tasked to carry out specific work. They may also direct and monitor specific activities carried out by task forces. Examples of such committees include Finance, Finance Advisory, Elections and Budget review.
- **Composition and Terms:** These are typically standing organizational entities. The Committee Chair and Members are appointed by the ILAE President in consultation with the Executive Committee, and their term expires with the term of the Executive Committee. The Past-Chair may remain a member of the new Committee. No member of the Committee can serve for more than one terms, unless appointed as Chair.
- A Management Committee Liaison is appointed by the ILAE President
- **Reporting structure:** Committees report directly to the Executive Committee.
- The Elections Committee is a special case, whose role, terms, and relation to the Executive Committee are described in Article I of the Bylaws and Article VIII of the Constitution.

F. *Task Forces*

- **Role and Responsibilities:** Task Forces are given specific and focused assignments under the direction of appropriate organizational entities, i.e., councils, commissions, Executive.
 - **Composition and Terms:** The term is task dependent. The Task force expires when its duties are completed. The Task Force Chair is appointed by the President in consultation with the Chair of the overseeing organizational entity. Members are selected by the Task Force Chair in consultation with the Chair of the overseeing entity.
 - **A Management Committee Liaison** may be appointed by the ILAE President
 - **Reporting Structure:** This will be determined by the specific task and overseeing body responsible, i.e., Chair of Commission, Council or to the Executive.
3. **Report of Activities:** All organizational entities will create and submit interim annual reports and submit a final report at the conclusion of the Executive Committee's term. Task Forces provide reports as needed to the overseeing body. All are encouraged to provide periodic progress reports to their Executive Committee liaison for review by the Executive Committee.
 4. Action items requiring Executive Committee approval or voting should be given to the appropriate Executive Committee Liaison in writing.
 5. Funds raised by an individual organizational entity, when not spent within the next fiscal year, may be allocated to the same organizational entity for the subsequent fiscal year, subject to the entity providing a plan for the utilization of the funds and approval of the plan by the Executive Committee.

- professionals working for epilepsy in that country, territory or region as defined in the Constitution.
2. Each Chapter must send to the ILAE Secretary-General the names and contact information of its officers within thirty days after the Chapter's General Assembly Meeting during which a new Executive Committee takes office. If changes in contact addresses occur these must be immediately reported to the Secretary General of the ILAE.
 3. Within thirty days after each Chapter's General Assembly meeting, the Chapter must submit any changes to its Constitution and Bylaws (in English) to the Secretary General.
 4. By March of each year, every chapter is requested to upload/enter their database, including email addresses of elected officers, to the ILAE website.
 5. Before October 1 of each year, each Chapter shall pay to ILAE, annual dues which shall be proportional to the number of dues paying members as of December 31 of the previous year, and shall be fixed for each fiscal period of the General Assembly. Dues for a Chapter are 3% of the annual dues that the Chapter charges each member, multiplied by the number of Chapter members, or a minimum payment of \$10 (U.S.) whichever is highest. In countries where exchange regulations do not allow for remittance of funds outside the country, then Escrow accounts may be established with the approval of the ILAE Treasurer.
 6. If a Chapter without consent of the Executive Committee omits paying its dues it will be once invited to do so, if the next year dues are again not paid, the Executive Committee may propose disaffiliation to the General Assembly in writing and/or have its right to vote at the meeting of General Assembly revoked. Two thirds of votes cast (with at least two thirds of all available votes having been cast) have to confirm disaffiliation.

Article VI – Chapters' Obligations

1. Chapters shall be open for membership to all

Article VII – Fiscal Year

The fiscal year of ILAE shall be January 1 through December 31.

Article VIII – Staff

1. The location of the ILAE's Headquarters Office will be determined by the Executive Committee.
2. The Executive Committee is empowered to retain such staff and contract for other professional services as may be necessary to carry out the functions of the League.

Article IX – Meetings

1. The International Congress of ILAE shall be held ordinarily every two years, in conjunction with the International Bureau for Epilepsy.
2. In the year between two International Congresses of the ILAE, the Regional Divisions of the ILAE will organize Regional Congresses with the support of the ILAE.
3. The ILAE may sponsor or support, wholly or in part, other meetings relevant to its objectives. Such a meeting shall not be designated as an International Congress of the League.

Article X – Endorsement of guidelines

1. The ILAE will not endorse guidelines/reports of other organisations unless the League is officially participating in their development from the outset

Article XI – Regions

1. Regional boards should meet from one to three times a year and must submit an annual budget for approval to the Executive Committee.
2. Regional boards should aim to develop, stimulate and coordinate the epileptology agenda in their part of the world.
3. Regional boards should promote the activities of local chapters, encourage similar policies and administrative structures and facilitate their involvement within the global ILAE agenda.
4. Regional boards can have designated funds which they access via the budget process

5. Regional boards should coordinate local educational activities
6. Regional boards should run their congresses under the direction of the International Director of Meetings.
7. Regional boards 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 boards should develop documents with the aim of stimulating local medico-political initiatives and improving patient care.
9. Chapters can belong to only one region.

Article XII – Cooperation with the International Bureau for Epilepsy (IBE)

1. ILAE shall cooperate with IBE on all levels: international, national, regional, and chapter to ensure maximum efficiency in promoting quality of life for people with epilepsy.
2. Each ILAE chapter shall promote the establishment and/or assist in establishing a chapter of the Bureau, if such a chapter does not exist.
3. At least annually, and more frequently if necessary, the Executive Committee shall meet jointly with the Executive Committee of the IBE, to consider matters of mutual interest and/or responsibility to both Executive Committees. Such a meeting shall be known in full as a Joint Meeting of the Executive Committees of the ILAE and IBE, and in brief as a JEC.
4. A JEC shall have no financial or constitutional power or existence independent of the Executive Committees of the ILAE and IBE. It is a meeting of two separate and independent constitutionally defined bodies, not an entity in itself.
5. Matters to be considered by a JEC shall include co-organized Epilepsy Congresses and the Global Campaign, and such other matters as the ILAE and IBE Executive Committees shall consider appropriate to be delegated to consideration and decision by a JEC.

Bylaws *(continued)*

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 XIII – Indemnification

Executive Committee members, officers, and other authorized staff, volunteers, or agents of the ILAE shall be indemnified against claims arising in connection with their positions or activities on behalf of the ILAE to the full extent permitted by law.

Article XIV – 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.

17,000

Members

122

Chapters

7

Congresses

4

Journals

1

Goal:

A world where no person's
life is limited by epilepsy



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