

A Global Agenda

2017 ANNUAL REPORT



TABLE OF CONTENTS

GOVERNANCE

Executive Committee List	3
President's Report	4
Treasurer's Report	6
<i>Epilepsia</i>	8
<i>Epileptic Disorders</i>	10
<i>Epilepsia Open</i>	12
Wikipedia	15
Director of Interactive Media	16
Headquarters/Chapter Services.....	18
Int'l Director of Meetings.....	19

TASK FORCES

Budget Review Task Force	24
Epilepsy Education Task Force	25
Epilepsy Guidelines Task Force	26
Global Outreach Task Force	28
Joint ILAE-IFCN EEG Database Task Force	29
Next Generation Task Force.....	30
Nosology and Definitions Task Force	31
Young Epilepsy Section	32

REGIONAL COMMISSIONS

ILAE-Africa.....	34
ILAE-Asia Oceania.....	35
ILAE-Eastern Mediterranean	36
ILAE-Latin America	37
ILAE-North America.....	39

TOPIC-ORIENTED COMMISSIONS

Diagnostic Methods.....	41
Epidemiology	42
Medical Therapies.....	44
Neurobiology.....	46
Pediatrics	52
Psychiatry.....	53
Surgical Therapies	54

CONSTITUTION	58
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BYLAWS.....	61
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Headquarters Office

2221 Justin Rd, #119 - 352,
Flower Mound, TX, USA
75028
Tel +1 860.586.7547
Fax: +1 860.201.1111
<https://www.ilae.org>

Chapter Services Office

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

EXECUTIVE COMMITTEE

2017-2021

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Samuel Wiebe
Canada

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Edward Bertram, III
USA

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Switzerland

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Israel

PRESIDENT'S REPORT



Samuel Wiebe

This year has marked the transition to the new leadership team of the ILAE, which commenced its work officially in September of 2017. The Executive Committee is the group in charge of deciding on all strategic aspects of the ILAE, and it consists of the elected Chairs of each of the six ILAE Regions, plus the Management Committee as voting members, as well as ex-officio and non-voting members from the International Bureau for Epilepsy and journal Editors. The six elected Regional Chairs are Roberto Caraballo (Latin America), Akio Ikeda (Asia-Oceania), Nathalie Jetté (North America), Angelina Kakooza (Africa), Chahnez Triki (Eastern-Mediterranean), and Eugen Trinkka (Europe). The Management Committee is the group in charge of implementing the ILAE mission and dealing with day-to-day operations. This is composed of four people, which include me as President, Ed Bertram as Secretary General, Helen Cross as Treasurer, Alla Guekht as Vice-President and Emilio Perucca as Immediate Past President. In addition, Jean Gotman serves as Strategic Advisor.

The new leadership team has been hard at work assembling the new Commissions and Task Forces that will carry out the vision and goals for this term. The core leadership of 25 new Commissions and Task Forces is now in place. These will eventually comprise about 400 top epilepsy professionals who will be the engine that propels us toward our goals by carrying out specific tasks and projects.

Our five global aims are 1) to improve access to care, 2) create new knowledge, 3) translate

knowledge into clinical care through education, 4) ensure financial sustainability and growth of the organization, and 5) increase collaborations. An overarching goal has been to engage the next generation of epileptologists in all the League's activities, and to this end a "Next Generation" Task force is being created.

To achieve these goals, the core undertakings of the League are strengthened through commissions such as diagnostics, medical and surgical therapy, paediatrics, psychiatry, neurobiology, epidemiology and genetics. In addition, new areas are under development and growth, such as guideline development, new education strategies, data sharing and big data models, addressing nosology and definitions in epilepsy, improving the standards of scientific research in epilepsy, developing leaders, and liaising with other international organizations. There is ongoing support for the work of the teams that are responsible for the more pragmatic aspects of the League through committees such as finance, budget review, congress organization, publications, communication and administration. Finally, there is a focus on continuously improving the quality and service provided by our three main journals, *Epilepsia*, *Epilepsia Open*, and *Epileptic Disorders*, and our nascent initiative in the Wikipedia Epilepsy Project.

We are fortunate to have a strong financial base for the ILAE. This has been due in part to a strong performance of the financial market in 2017. But most importantly, to the adoption of fiscally responsible policies and sound business decisions

PRESIDENT'S REPORT *(continued)*

with regard to our journals and investments. We have to thank our excellent team of finance advisors for their guidance and for embracing the mission of the League with such dedication. What this means for the new term is an outlook of cautious optimism. Our healthy financial situation allows us to consider new possibilities for development, more effective work, and better education and care for people with epilepsy around the world.

Achieving our goals will require energy and dedication, but especially collaboration and

transparency. Accordingly, we plan to launch a wide-ranging consultation campaign to learn what aspects of our congresses, education, and publication we need to modify or strengthen to serve you better. New ideas and new approaches are welcome. Making those new ideas a reality will require our collective effort. The new leadership team is energized and ready, and I look forward with excitement to the term ahead.

Samuel Wiebe
President

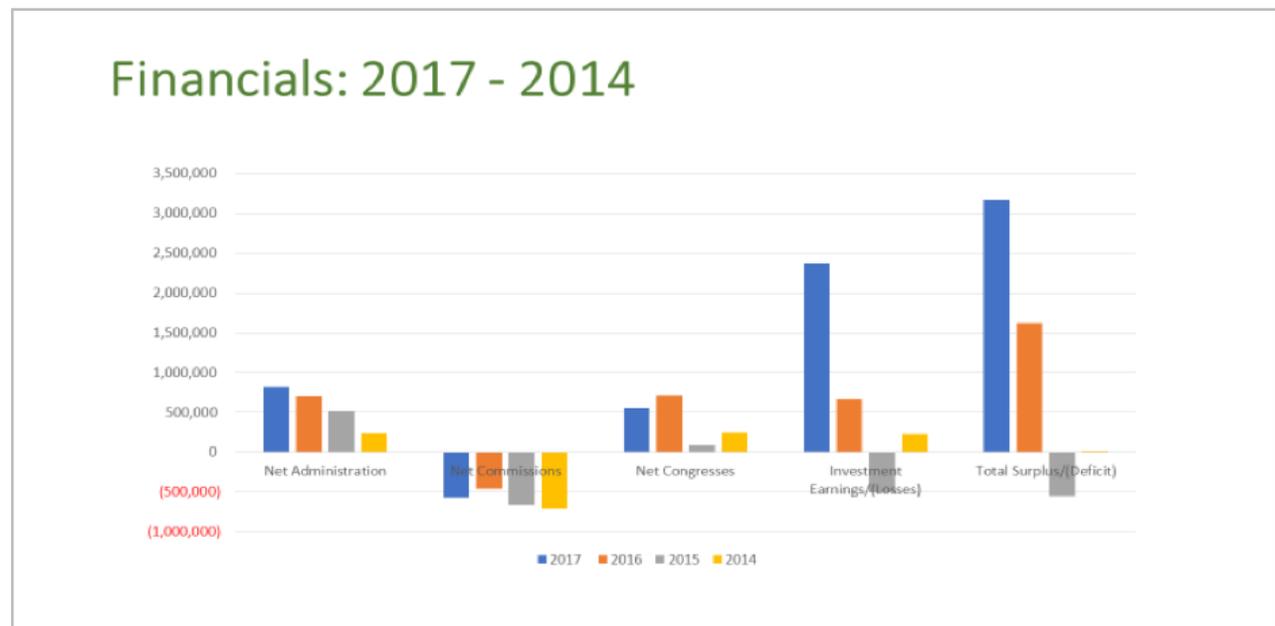
TREASURER'S REPORT



Helen Cross

It is a great privilege to have been re-elected to the Management Committee, and indeed to have been appointed Treasurer for the term 2017-2021. I have taken on the role at a time when we are financially in good shape. The challenge for us in the near future will be to preserve our endowment to enable increased support of mission driven initiatives. We are ever grateful to our group of financial volunteers who advise us through the Financial Advisory Committee. Over the upcoming 12 months, we will continue to seek advice, as well as to improve efficiencies where possible.

The chart below shows our four main budget categories; Administration, Commissions, Congresses and Investments, as well as their net activity over the past four years. As illustrated, positive net administrative and congress activities support our commissions, allowing us to use the investment earnings to reach our endowment target.



With regards to congress finances, we continue to remain in challenging times. Over the past few years, we have reduced registration fees even while facing a reduction in industry support. Yet despite these reductions, we have maintained a quality scientific programme while generating surpluses used to support operations and our commissions. With regards to our congress programme, we recognise that the needs of the community may vary according to region; consequently, we are re-assessing the structure and organisation of the congresses to determine whether we are meeting these needs. I am chairing a task force formed to reassess these needs; we will seek opinions from the community and report within the next year.

Our publications include *Epilepsia*, *Epilepsia Open* and, our education journal, *Epileptic Disorders*. The impact factors have improved over the past few years, resulting in higher than budgeted royalties. New initiatives include the launching of Wikipedia, a redesign of the website and an emphasis on education spearheaded by the Epilepsy Education Task Force.

Other important ILAE initiatives center around the younger generation of epileptologists. One initiative that began at the International Congress in Barcelona is a mentor/mentee programme that provides junior researchers the opportunity to meet and gain experience from more senior individuals. This was such a great success that it will be offered at other congresses. Other career developing opportunities are offered through the leadership programme, which includes individuals from IBE and ILAE. This programme, initially offered during the International Congresses, has become so successful that it is also now offered at the regional

congresses. Another initiative that I've been integrally involved in is the Young Epilepsy Section (YES). To kick off the initiative, a workshop was held in London in May 2018, and representation was established from all regions. We will continue to provide support for the younger generations as they are the future of the League.

Helen Cross
Treasurer

EPILEPSIA REPORT



Astrid Nehlig



Michael Sperling

EPILEPSIA

In 2017, *Epilepsia* had another successful year. In bibliometric terms, in 2017 *Epilepsia* was ranked 22nd of 194 journals in the Clinical Neurology category, had an Impact Factor (IF) of 5.295, a h-index of 161 and an Eigenfactor of 0.041. The *Epilepsia* IF has been steadily increasing over the last 5 years and increased from 4.584 in 2013 when we became the editors of the journal, to 5.295 in 2016/2017. It remains higher than that of any of the other epilepsy sub-specialty journals, with the exception of *Epilepsy Currents* (IF for 2017: 5.625). The objective of the previous years was to try to increase the impact factor, and to reach the magic number of 5.0 which will attract more interest and even higher quality publications, mainly in basic science and especially from Europe. This goal has now been achieved; the next objective is being to stabilize the IF over 5.0 and if possible, increasing it further, closer to 6.0 in the next three years.

Volume 58 (calendar year 2017) comprised 2,584 printed pages and 148 e-only pages, which included twelve regular monthly issues.

The following supplements were also published:

- S1: *Pediatric Surgery*, 90 pages, – Arthur Cukiert and Bertil Rydenhag, guest editors
- S2: *Hypothalamic Hamartomas*, 96 pages, – Jean Régis and Jack Kerrigan, guest editors
- S3: *Immunity and Inflammation in Epilepsy (IIE2016)*, 84 pages, – Annamaria Vezzani and Stephan Rüegg, guest editors
- S4: *Harmonization in Preclinical Epilepsy Research*, 88 pages, – Jacqueline A. French, Aristeia S. Galanopoulou, Terence J. O'Brien and Michele Simonato, guest editors
- S5: *Special Issue: 22nd International Epilepsy Congress, Barcelona, Spain*, 225 e-only pages.

STATISTICS OF EPILEPSIA FOR 2017:

Epilepsia Statistics for 2017 are listed below in terms of number of manuscripts submitted and accepted for each category of papers published in the journal.

	Total number of manuscripts	Reviews	Full length original research articles	Brief communications	Special reports (ILAE Commissions)	Supplements	Gray Matter material
# submitted	1135	49	792	188	8	58	34
# accepted	285	25	165	25	2	50	18
% accepted	25%	51%	21%	13%	25%	86%	53%

EPILEPSIA REPORT *(continued)*

MANUSCRIPTS REJECTED

Epilepsia Statistics for 2017 are listed in terms of number of manuscripts rejected in every category of rejection.

Decision	# Manuscripts	Percentage
Direct reject	207	24%
Direct reject with transfer to EO	259	30%
Direct reject with transfer to EPD	27	3%
Direct reject with resubmission option	32	4%
Reject after review	325	38%
TOTAL	850	100%

The editors balance the inclusion of papers likely to be cited and consider novelty as one of the most prominent criteria to select papers for review. They also consider as an equally important goal, to serve the epilepsy research community by publishing a range of other reports. Financially, the Journal remains highly successful, bringing in net income to ILAE of over US\$1 million.

In terms of circulation and readership, in 2017, 6,116 institutions offered access to *Epilepsia* either through a license or a traditional (title-by-title) subscription. Licensed subscriptions grew by 14% from 5,276 to 6,036. The increase in licensed access typically means a decrease in title-by-title subscriptions. In 2017, transitional subscriptions dropped by 8% from 87 to 80. In addition, Hinari philanthropic initiatives extended low-cost or free access to current content in 2017 to 7,669 developing world institutions.

In 2017, there were over 1,950,000 full-text downloads of *Epilepsia* content, reflecting a 25% increase from the preceding year.

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

EPILEPTIC DISORDERS



Alexis
Arzimanoglou

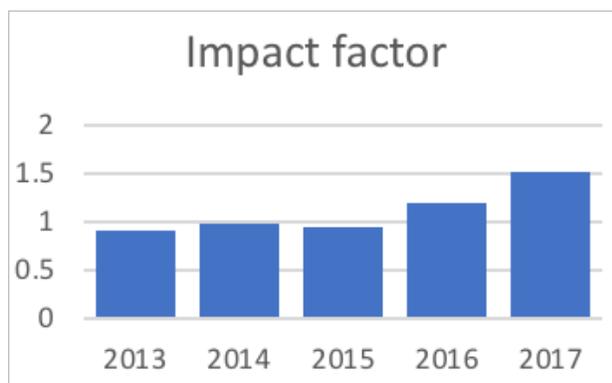
Editor-In-Chief:

Alexis Arzimanoglou, France

Associate Editors:

Ingmar Blümcke, Germany
Michael Duchowny, USA
Aristea Galanopoulou, USA
Alexander Hammers, UK
Yushi Inoue, Japan
Philippe Kahane, France
Michalis Koutroumanidis, UK
Doug Nordli, USA
Lieven Lagae, Belgium
Guido Rubboli, Denmark
Graeme Sills, UK
Pierre Thomas, France
Torbjörn Tomson, Sweden
Sarah Wilson, Australia

2017 has been a good year for *Epileptic Disorders*, reflected by an increase in impact factor to 1.5, which is the highest to date. With the now close collaboration with *Epilepsia* and *Epilepsia Open*, we are confident that this will further increase.



However, success is not simply reflected by impact factor; the educational contribution to the epilepsy community is also an important measure. In line with its educational role, the journal continues to publish questions and answers that accompany manuscripts, review and seminar style papers, electroclinical reasoning reports, and multimedia teaching material.

In 2017, 143 manuscripts were submitted, consisting of original articles (54) and clinical commentaries (69), reviews (7), seminars in epileptology (4), electroclinical reasoning reports (2), and multimedia teaching material (7). The acceptance rate over 2017 was 44%.

The *Epileptic Disorders* website (www.epilepticdisorders.com) is constantly being developed as an educational resource centre.

Website Visitors

The number of visitors to the website has increased to 97,566 in 2017 (from 91,899 in 2016), and the most frequently accessed manuscripts were (in order):

- The role of EEG in the diagnosis and classification of the epilepsy syndromes: A tool for clinical practice by the ILAE Neurophysiology Task Force (Part 1)

Michalis Koutroumanidis, Alexis Arzimanoglou, Roberto Caraballo, Sushma Goyal, Anna Kaminska, Pramote Laoprasert, Hirokazu Oguni, Guido Rubboli, William Tatum, Pierre Thomas, Eugen Trink, Luca Vignatelli, Solomon L. Moshé

- The role of EEG in the diagnosis and classification of the epilepsy syndromes: A tool for clinical practice by the ILAE Neurophysiology Task Force (Part 2)

Michalis Koutroumanidis, Alexis Arzimanoglou, Roberto Caraballo, Sushma Goyal, Anna Kaminska, Pramote Laoprasert, Hirokazu Oguni, Guido Rubboli, William Tatum, Pierre Thomas, Eugen Trink, Luca Vignatelli, Solomon L. Moshé

- Sudden unexpected death in epilepsy (SUDEP): What every neurologist should know

Rohit Shankar, Elizabeth J. Donner, Brendan McLean, Lina Nashef, Torbjörn Tomson

- Epilepsy after cerebral infection: Review of the literature and the potential for surgery

Georgia Ramantani, Hans Holthausen

EPILEPTIC DISORDERS *(continued)*

- Atlas of electroencephalography, 3rd Edition
Ali Akbar Asadi-Pooya, Dennis Dlugos, Christopher Skidmore, Michael R Sperling
- Seizure semiology of anti-LGI1 antibody encephalitis
Nicholas J. Beimer, Linda M. Selwa

Manuscript Citations

The most frequently cited manuscripts in 2017 were (in order):

- Incidence, prevalence and aetiology of seizures and epilepsy in children
Peter Camfield, Carol Camfield
- From here to epilepsy: The risk of seizure in patients with Alzheimer's disease.
Nicolas Nicasro, Frederic Assal, Margitta Seeck
- Vagus nerve stimulation in children with drug-resistant epilepsy: Age at implantation and shorter duration of epilepsy as predictors of better efficacy?
Lieven Lagae, An Verstrepren, Ayman Nada, Johan Van Loon, Tom Theys, Bertien Ceulemans, Katrien Jansen.
- Efficacy and safety of lacosamide as an adjunctive therapy for refractory focal epilepsy in paediatric patients: A retrospective single-centre study.
Jean-François Toupin, Anne Lortie, Philippe Major, Paola Diadori, Michel Vanasse, Elsa Rossignol, Guy D'Anjou, Sebastien Perreault, Albert Larbrisseau, Lionel Carmant, Ala Birca.

To promote readership and circulation, John Libbey Eurotext maintains a regular mailing system involving the circulation of newsletters (of which 38 were sent in 2017), invitations to submit multimedia teaching material, and announcements to an extensive mailing list within the epilepsy community worldwide (>27,000 addresses). The Newsletter also regularly promotes educational manuscripts from our archives. All publications in *Epileptic Disorders* become open access 12 months after their release. Since the beginning of 2017, 85 new ILAE members have subscribed.

Collaboration between JLE and Wiley is now regular, helping in a much larger diffusion of the journal. Early Editions of Ahead of Prints progressively became a constant feature of the journal.

2018 Plans

Our plans for 2018 include:

- Reinforcing the educational profile of the journal and pursuing our policy to also consider for publication novel and didactic case reports of interest to practicing physicians as a demonstration of a comprehensively structured electro-clinical reasoning.
- Increasing the number of issues per-year (6 instead of 4).
- Moving to an e-journal only edition with videos, also offering to subscribers the option to download not only individual manuscripts but a whole issue.

EPILEPSIA OPEN



Aristeia Galanopoulou,
New York, NY, USA



Dieter Schmidt,
Berlin, Germany



Xuefeng Wang,
Chongqing, China

Editors-in-Chief

Aristeia Galanopoulou, The Albert Einstein College of Medicine, Bronx, NY, USA

Dieter Schmidt, Emeritus Professor of Neurology, Berlin, Germany

Xuefeng Wang, The First Affiliated Hospital of Chongqing Medical University, Chongqing, China,

Associate Editors

Ettore Beghi, IRCCS-Istituto di Ricerche Farmacologiche "Mario Negri", Milan, Italy

Kees Braun, University Medical Center Utrecht, Brain Center Rudolf Magnus, Utrecht, the Netherlands

Roland Coras, University Hospital Erlangen, Erlangen, Germany

Lara Jehi, Cleveland Clinic Epilepsy Center, Cleveland, OH, USA

Andrey Mazarati, Developmental Epilepsy Research Laboratories, David Geffen School of Medicine at UCLA

Terence O'Brien, The Royal Melbourne Hospital, Victoria, Australia

Manisha Patel, University of Colorado Anschutz Medical Campus

Philippe Ryvlin, CHUV, Lausanne, Switzerland, Epilepsy Institute IDEE, Lyon, France

Rainer Surges, University Hospital, Bonn, Germany

Michael Rogawski, School of Medicine, University of California, Davis

Michael Wong, Washington University in St Louis, Missouri

Mark Cook, University of Melbourne, Melbourne, Australia

Jan Gorter, University of Amsterdam, Amsterdam, Netherlands

Editorial Board

Melissa Barker-Haliski, University of Washington, Seattle, WA, USA

Sallie Baxendale, Institute of Neurology, London, United Kingdom

Neda Bernasconi, McGill University, Montreal, QC, Canada

Ingmar Blümcke, University Hospital Erlangen, Erlangen, Germany

Chad Carlson, Medical College of Wisconsin, Milwaukee

Carlos Cepeda, University of California, Los Angeles, Los Angeles, CA, USA

Petia Dimova, St. Ivan Rilski University, Sofia, Bulgaria

Raymond Dingledine, Emory University, Atlanta, GA, USA

Elizabeth Donner, The Hospital for Sick Children, Toronto, ON, Canada

Nigel Jones, University of Melbourne, Parkville, VIC, Australia

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Marco Medina, National Autonomous University of Honduras, Tegucigalpa, Honduras

Wenzhu Mowrey, Albert Einstein College of Medicine New York, NY, USA,

Marco Mula, St George's Hospital, London, United Kingdom

EPILEPSIA OPEN *(continued)*

Rima Nababout, APHP, Necker Enfants Malades Hospital, Paris, France

Tomonori Ono, National Nagasaki Medical Center, Omura, Japan

Asla Pitkanen, University of Eastern Finland, Kuopio, Finland

Joseph Raimondo, University of Cape Town, Cape Town, South Africa

Jong M. Rho, University of Calgary, Calgary, AB, Canada

Harvey Sarnat, Alberta Children's Hospital, Calgary, AB, Canada

Stephan Schuele, Northwestern University, Chicago, IL, USA

Prabha Siddarth, UCLA, Los Angeles, CA, USA

Michele Simonato, University of Ferrara, Ferrara, Italy

Roland Thijs, Stichting Epilepsie Instellingen Nederland – SEIN Heemstede, the Netherlands

Igor Timofeev, Université Laval, Québec, QC, Canada

Sarah Wilson University of Melbourne, Melbourne, VIC, Australia

Elaine Wirrell Mayo Clinic, Rochester, MN, USA

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.

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."

The Editors in Chief and Editorial Board, in collaboration with Wiley and the ILAE leadership where needed, have been convening via teleconferences or face-to-face meetings (Hoboken 2017, IEC Barcelona 2017, AES meeting DC 2017) to discuss the progress, strategies and action items, and advance the quality of the journal. As a result, there has been continuous improvement in the submission and journal website, author instructions, and content of the journal, as discussed in the following sections. There has also been frequent communication with the *Epilepsia* editors on papers that could potentially be transferred to *Epilepsia Open*.

Accomplishments (2016-2017 and first quarter of 2018)

Editorial Board

The terms of Drs Galanopoulou, Schmidt and Wang were extended to continue acting as editors-in-chief from September 2017 until August 2018. The terms of most of the editorial board members were also extended (see above list) and encompass experts from various countries and of diverse expertise, including clinical, basic science, or statistical expertise.

Marketing and increasing awareness of the journal

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

Special efforts to attract submissions and increase awareness about the journal have been done through Wiley and the editor-in-chief, Dr Wang, in China, which resulted in a recent increase in submissions.

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

Published issues

In 2017, *Epilepsia Open* published 4 issues, each including 9-18 articles, including original research, critical reviews, ILAE reports, invited commentaries and case reports. There has been an increasing trend of citations for each of these articles and currently one-third of these articles have received citations. The first impact

EPILEPSIA OPEN *(continued)*

factor for *Epilepsia Open* is expected in 2019. The number of published articles has been sufficient to meet criteria for applying for inclusion in Pubmed Central (PMC).

Submissions

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

- (a) Transfers from *Epilepsia*: We currently receive as submissions to *Epilepsia Open* 15% of the articles that we had offered to transfer from *Epilepsia*. In 2017, these comprised approximately 68% of the total submissions to *Epilepsia Open*. The acceptance rate was 77.3% in 2017 and 86% in 2018. In the first quarter of 2018, a trend for more direct submissions to *Epilepsia Open* was noted and transferred articles comprised only 39.5% of all submissions.
- (b) Direct submissions to *Epilepsia Open*: Direct submissions in 2017 comprised 31.5% of total submissions to *Epilepsia Open*, but this was further increased in the first quarter of 2018 (60.5%), along with an overall increase in total submissions. The acceptance rate was 63% in 2017 and 91% in 2018.

The majority of the articles are full length original research (48%), or short research reports (23.7%); critical reviews or commentaries comprise 10% of articles, special reports 3.5% and the rest are editorials, invited original research, and hypothesis articles. Most of the articles are clinical, including case reports (92.4%) and a small proportion are basic science (<2% in 2017, 9% in 2018 so far).

In 2017, 52% (28/54) of the manuscripts that have been exported through to production have paid APCs. The countries of origin of these submissions with paid APCs are: USA, Canada, Japan, UK, Netherlands, Ireland, Austria, New Zealand and Portugal.

Leading submitting countries are USA (30%), UK, Netherlands, Japan, Canada, Italy, India, and Australia. Leading publishing countries are USA (33.3%), UK, Netherlands, Canada, Italy, Japan and Australia.

The editors-in-chief have also accommodated APC waivers to authors who have requested a waiver, in accordance with our decision to facilitate publications in our journal from authors who would have difficulty meeting the APC requirements.

Special Issues

Two special issues are planned for 2018. The first will include the preclinical common data elements (CDEs) for epilepsy that have been prepared by the TASK3 group of the ILAE/AES Joint Translational Task Force (guest editors: Drs Galanopoulou, Scharfman, Harte-Hargrove, French, Whittemore, Pitkanen). The second is a special issue on epilepsy therapies in honor of Dr Raman Sankar (guest editors Drs Mazarati and Moshé).

Indexing

The application for the Directory of Open Access Journals (DOAJ) has been approved and as of March 2018, the application for PMC inclusion was also approved. Currently most of the *Epilepsia Open* articles have appeared in the Pubmed. The application for EMBASE has been submitted and there is a plan to apply for ESCI, Medline and SCOPUS.

Recommendations for Future Work

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

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

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

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

Aristea Galanopoulou, Dieter Schmidt,
and Zuefeng Wang
Co-Editors-in-Chief, *Epilepsia Open*

WIKIPEDIA



Günter Krämer



Nicola Maggio

In 2017, a collaboration was established between the ILAE Wikipedia Initiative and the American Program at the Sackler Faculty of Medicine, Tel Aviv University. In this frame it was established that from 2018, the Wikipedia editing course offered to medical students enrolled in the program will offer the possibility to edit/create Wikipedia related epilepsy entries.

Günter Krämer and Nicola Maggio
Co-Editors-in-Chief, Wikipedia Epilepsy

DIRECTOR OF INTERACTIVE MEDIA



Jean Goiman

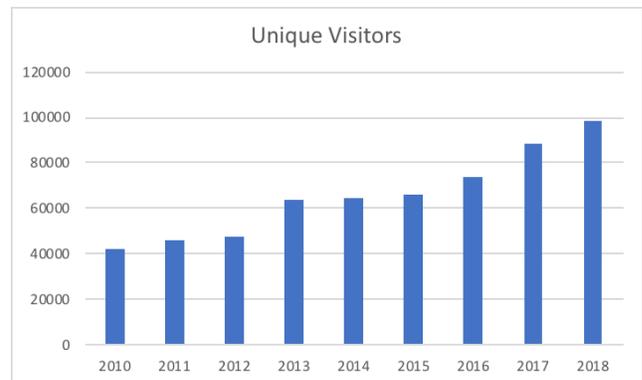
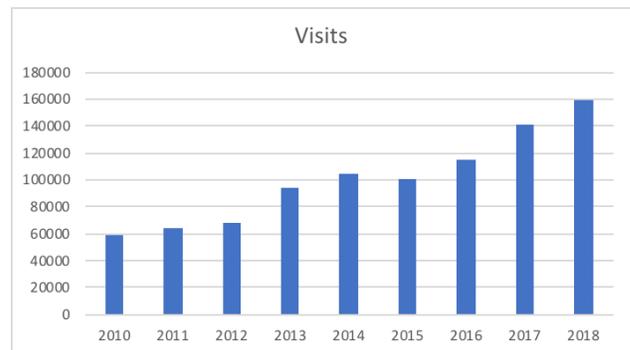
WEBSITE RESTRUCTURING

In 2017, the web team completed a major project to change the structure of the website. The entire site contents were moved to a content management system, and at the same time, all membership data and photos that fed the site were moved to a new database system. These structural changes represented the bulk of the work but they are not apparent to the casual observer of the site. We also made an effort to give the site a modern style, and the site is now “responsive,” which means that it automatically sizes the content to fit the device being used. It is important to ensure readability at all screen sizes because an increasing number of visitors access the site by mobile device (see graph below). This restructuring took all the team’s available time from October 2016 to the launch of the new site, at the end of August 2017.

Behind the scenes, the content database enables information to be easily “tagged” to appear in – or be removed from – multiple site locations. One example where this is easily apparent is the congresses. Each congress is tagged by type, e.g., “ILAE chapter”, as well as by region or commission, so that it will appear on the events pages for each. A link to any congress can also be easily inserted on any other page in the website. After the congress date, it is automatically removed from each of these locations, but is still available under Past Congresses in the regional and congress areas of the site.

Visits to the web site

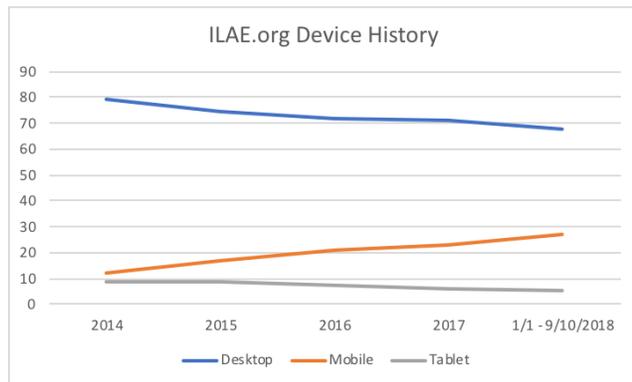
Because of the restructuring of the site (and the change from an “http” to the more secure “https”), statistics covering the whole year (including the old and the new site) would be complex to obtain. We therefore opted to show statistics for the first 6 months of the year, for past years, for 2017, and we included 2018 even though this report is for 2017. We have verified that in past years, the yearly total is very close to twice the 6-month values. Charts below are therefore for January through June for 2010-2018. They show a nice increase in visits to the ILAE site.



DIRECTOR OF INTERACTIVE MEDIA *(continued)*

Devices

One reason for creating the new web site was to make it responsive to the smaller screens of mobile devices. 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.



e-Newsletters

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

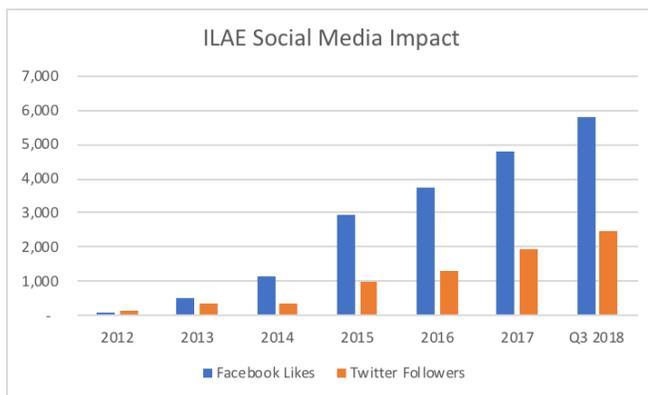
Operations

Deb Flower continues to run the web site, social media and e-newsletters, during the 20 hours per week that she works for the ILAE. She is supervised by Priscilla Shisler and Jean Gotman. The team meets for a conference call weekly and exchanges multiple daily emails. The development of the new web site was largely done by an outside contractor.

*Submitted by
Jean Gotman, Deb Flower, Priscilla Shisler*

Social Media

We have put a lot of emphasis on posting all news items to social media, and this has resulted in a clear increase in the number of individuals following the ILAE.



HEADQUARTERS/ CHAPTER SERVICES



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



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



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



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 Commission on the elections process for the Executive and Regional Commissions

ILAE-IBE INTERNATIONAL DIRECTOR OF MEETINGS

Report on Congresses July 2016 – December 2017



Richard Holmes

From July 2016 to December 2017, the Congress Team managed the **9th Latin American Congress on Epilepsy**, the **12th European Congress on Epileptology**, the **14th European Conference on Epilepsy & Society**, the **4th East Mediterranean Epilepsy Congress**, the **3rd African Epilepsy Congress**, and the **32nd International Epilepsy Congresses**.

These congresses had a total of 7,067 attendees, 612 speakers and Chairs, 2,332 abstracts received and 187 bursaries awarded.



9th Latin American Epilepsy Congress, Cancun, Mexico **20th-23rd August 2016**

The organising committee, chaired by Marco Tulio Medina (Honduras), Tomás Mesa (Chile) and Gerardo Quiñones (Mexico), comprised 9 members. The venue was the Cancun ICC International Convention Centre. There were 803 attendees and 33 countries were represented.

Congress programme:

- The programme comprised 44 sessions, with 100 speakers and Chairs.
- The programme was created by the International Scientific and Organising Committee incorporating proposals submitted by ILAE and IBE Chapters, and commissions/committees and experts in the field.
- The scientific programme had a wide range of sessions and the specially-created Presidential Symposium.
- Four ALADE Courses and a Neurobiology Workshop were held on Saturday, and an IBE day also took place all day.
- 8 abstracts were selected for platform presentation in 2 sessions.
- A stimulating education programme with 7 morning Teaching Sessions and a teaching day with 3 Teaching Courses was offering.
- 187 abstracts were received and 36 bursaries were awarded.

PRAGUE **12th European Congress on Epileptology, Prague, Czech Republic**



11th-15th September 2016

The organising committee, chaired by Meir Bialer (Israel) and Milan Brázdil (Czech Republic), comprised 12 members. The venue was Prague Congress Centre. There were 2,309 attendees and 87 countries were represented.

Congress programme:

- The programme comprised 82 sessions, with 151 speakers and Chairs.
- The programme was created by the International Scientific and Organising Committee incorporating proposals submitted by ILAE, and IBE Chapters and commissions/committees and experts in the field. Main session topics: 'Trials and tribulations in the development of medical therapies'; 'The changing landscape of epilepsy surgery: Assessment and treatment'; 'Challenges in the management of epilepsy in children – systems and technology as solutions'; 'Neurogenesis in epilepsy'.
- The Chairs' Symposium: 'Pharmaco-resistant epilepsy from bench to seizure control'.
- The scientific programme had a wide range of Main and Parallel Sessions, Teaching Sessions, debates, ECE Forums and Video Sessions, and ended with a Highlights Session. Two special symposia: CEA-EAN (European Academy of Neurology) Symposium and CEA-EMA (European Medicines Agency) Symposium.
- 114 abstracts were selected for platform presentation in 19 sessions.
- A stimulating education programme with 7 morning Teaching Sessions and a teaching day with 3 Teaching Courses was offered.

Other highlights:

- **Awards presented:**
 - European Epileptology Award 2016 - Pavel Mareš (Czech Republic)
 - European Epileptology Award 2016 - Federico Vigevano (Italy)

ILAE-IBE INTERNATIONAL DIRECTOR OF MEETINGS

Report on Congresses July 2016 – December 2017 *(continued)*

- European Epilepsy Education Award 2016 - Nana Tatishvili (Georgia)
- CEA Young Investigator Award 2016 - Julia Jacobs (Germany)
- CEA Young Investigator Award 2016 - Nicola Specchio (Italy)
- Epileptic Disorders Educational Prize - Ioana Mindruta (Romania)

- 817 abstracts were received and 42 bursaries were awarded.



14th European Conference on Epilepsy & Society, Prague, Czech Republic

15th-16th September 2016

The organising committee was comprised of the IBE-EREC committee and chaired by Tata Vasou (Greece). Other members included Athanasios Covanis (Greece), Maggan Andersson (Sweden), Michael Alexa (Austria), Sari Tervonen (Finland), Janet Misfud (Malta), Ljubica Vrba (Slovenia), Ann Little (Ireland) and Shirley Maxwell (UK). There were 101 registered attendees.

Congress programme:

- The programme comprised of 7 sessions over two days, with 18 speakers and Chairs.
- The programme was created by the IBE-EREC committee as a result of ongoing communication and teleconference calls.
- The scientific programme had a wide range of sessions relating to Epilepsy and Society including a joint IBE-EREC and ECE session, 'Epilepsy 2020'; 'Epilepsy and Memory'; 'Fundraising and Epilepsy'; 'Education and Employment'.
- 3 bursaries were awarded.



4th East Mediterranean Epilepsy Congress, Luxor, Egypt

LUXOR
4th EAST MEDITERRANEAN EPILEPSY CONGRESS
16th-18th FEBRUARY 2017

16th-18th February 2017

The organising committee, chaired by Hassan Hosny (Egypt), Chahnez Triki (Tunisia) and Nirmeen Kishk (Egypt), comprised 8 members. The venue was the Steigenberger Nile Palace Hotel. There were 352 attendees and 30 countries were represented.

Congress programme:

- The programme comprised 14 sessions, with 49 speakers and Chairs.
- The programme was created by the Scientific and Organising Committee incorporating proposals submitted by ILAE and IBE Chapters and commissions/committees. Session topics included: 'Managing pharmaco-resistant epilepsy'; 'Drug-resistant epilepsy'; 'Status epilepticus'; 'Generalized epilepsies of unknown and genetic cause'; 'Epileptic encephalopathies'; 'Immune-mediated epilepsies'; 'School and epilepsy'; 'Perceptions and understanding of epilepsy among the general public'.
- The scientific programme had a range of sessions, Teaching Sessions and Teaching Courses, and ended with take-home messages in a closing remarks session. There was a special 'WFN/CEMA Session'.
- 4 abstracts of exceptional standard were selected for platform presentation.
- A stimulating education programme with morning Teaching Sessions each day, a pre-congress 'Educational course on multiple sclerosis' and a pre-congress 'Basic EEG teaching course' was offered.
- 41 abstracts were received and 5 bursaries were awarded.

ILAE-IBE INTERNATIONAL DIRECTOR OF MEETINGS

Report on Congresses July 2016 – December 2017 *(continued)*



5th-7th May 2017

The organising committee, chaired by Amadou Gallo Diop (Senegal), Youssouf Noormamode (Mauritius) and Moustapha Ndiaye (Senegal), comprised 8 members. The venue was the Centre de Conférences UCAD II. There were 281 attendees and 48 countries were represented.

Congress programme:

- The programme comprised 21 sessions, with 79 speakers and Chairs.
- The programme was created by the Scientific and Organising Committee incorporating proposals submitted by ILAE and IBE Chapters and commissions/committees. Session topics included: 'Regional challenges in managing epilepsy'; 'Risk factors of epilepsy'; 'Diagnosis of epilepsy – practical aspects'; 'Management of epilepsies'; 'Epilepsy, society and cultural aspects'.
- The scientific programme comprised Main and Parallel Sessions, Teaching Sessions, Video Sessions and an IBE Symposium. Several Parallel Sessions were held simultaneously in French.
- A stimulating education programme was offered with morning Video Sessions and a Teaching Course 'From bedside to pharmacological treatment – diagnosis and treatment with antiepileptic drugs', which was a collaboration between The National Center for Epilepsy and Oslo and Akershus University College, Oslo, Norway.
- 106 abstracts were received and 25 bursaries were awarded.



2nd-6th September 2017

The organising committee, chaired by Emilio Perucca (Italy), Athansios Covanis (Greece), and Antonio Russi (Spain) comprised of 7 other members, Shinichi Hirose (Japan) Liset M de Prida (Spain), Rafal Nowak (Spain), Sari Tervonen (Finland), Rima Nabbout (France), Sheryl Haut (USA) and Philippe Ryvlin (Switzerland). The venue was Palau de Congressos de Catalunya. There were 3,221 attendees and 109 countries were represented.

Congress programme:

- The programme comprised 87 sessions, with 131 speakers and 84 Chairs.
- The programme was created by the Scientific and Organising Committee, incorporating proposals submitted by ILAE and IBE Chapters and commissions/committees and experts in the field. Main session topics included: 'Comorbidities', 'Precision medicine', 'Epileptic encephalopathies', 'Understanding the nature of seizures: Identifying the epileptic networks' and 'Novel technologies for epilepsy'.
- The Presidential Symposium: 'A New Classification is Born'.
- The scientific programme had a wide range of Main and Parallel Sessions, Teaching Sessions, debates, 'Ask the Expert' and video sessions, and ended with a Highlights Session.
- 75 abstracts were selected for platform presentation in 18 sessions.
- A stimulating education programme with 20 Teaching Sessions and 2 EEG Courses was offered.

ILAE-IBE INTERNATIONAL DIRECTOR OF MEETINGS

Report on Congresses July 2016 – December 2017 *(continued)*

Other highlights:

- Awards presented:
 - Lifetime Achievement Award - Charlotte Dravet (France)
 - Social Accomplishment Award- Susan Axelrod (USA)
- Ambassador for Epilepsy Awards:
 - Michel Baulac (France)
 - Giuseppe Capovilla (Italy)
 - Nathalie Jetté (Canada)
 - Jaideep Kapur (USA)
 - Astrid Nehlig (France)
 - Terence O'Brien (Australia)
 - Makiko Osawa (Japan)
 - Galo Pesantez Cuesta (Ecuador)
 - Parthasarthy Satishchandra (India)
 - Ivan Rektor (Czech Republic)
 - Eugen Trinko (Austria)
 - Sameer Zuberi (United Kingdom)
- 1,181 abstracts were received and 76 bursaries were awarded: 27 IBE Bursaries and 49 ILAE Bursaries.

Future Congresses

The Congress Team is currently working on arrangements for the upcoming congresses in 2018 (**12th Asian & Oceanian Epilepsy Congress**, Bali, Indonesia; **13th European Congress on Epileptology**, Vienna, Austria; **10th Latin American Congress on Epilepsy**, San Jose, Costa Rica) and 2019 (**5th East Mediterranean Epilepsy Congress**, Marrakech, Morocco; **33rd International Epilepsy Congress**, Bangkok, Thailand; **4th African Epilepsy Congress**, Kampala, Uganda), as well as the regional congresses in 2020, and the IEC and regional congresses in 2021.

Richard Holmes
International Director of Meetings



Task Force
Reports
2017 – 2021

BUDGET REVIEW TASK FORCE



Lynette Sadleir

Chair

Lynette Sadleir (New Zealand)

Members

Amza Ali (Jamaica)
Michel Baulac (France), Past Chair
Andrew (Andy) Cole (USA)
Alejandro de Marinis (Chile)
Richard Idro (Uganda)
Byung-In Lee (Korea)
Kristina Malmgren (Sweden)
Uma Menon (USA)
Gagandeep Singh (India)

MC Liaisons

Helen Cross (United Kingdom)

In 2017, the Budget Review Task Force held two brief (2 hour) face-to-face meetings (ILAE Congress 2017, AES 2017) where members became familiar with the review process in preparation for scoring of the 2018 budgets. We developed a new budget template for the 2018 budget submission. These were completed well by all of the Commission and Task Forces, and provided us with a good basis on which to score each budget.

For the 2018 budget process, we were sent 20 budgets from the ILAE Topical Commissions and Task Forces, with 146 individual activities to review. In a departure from previous years, we were not asked to score the budgets from the Regional Commissions. Budget Review Task Force members independently scored each activity in each budget on a 5-point scale, considering the activities' contribution to the strategic plan, methodology, and synergy with other commissions, milestones, deliverables, and the financial plan. The independent scores were then collated. At a ZOOM video-conference, members discussed all activities where there was a standard deviation >1 in collated scores. Twenty-nine activities were discussed and as a consequence, some scores were updated. The results of the scoring for all activities in each budget were sent to the ILAE Treasurer and Chair.

Lynette Sadleir
Chair, Budget Review Task Force

EPILEPSY EDUCATION TASK FORCE



Ingmar Blümcke



Wei-ping Liao

Co-Chairs

Ingmar Blümcke (Germany)
Wei-ping Liao (China)

Members

Alexis Arzimanoglou (France)
Sándor Beniczky (Denmark)
Jaime Carrizosa (Colombia)
Jean Gotman (Canada)
Günter Krämer (Germany)
Nicola Maggio (Israel)
Priscilla Shisler (USA)
Sarah Wilson (Australia)

MC Liaisons

Samuel Wiebe (Australia), Past Chair

The overall goal of the Task Force is to develop a certificate-based teaching curriculum for epileptologists. The curriculum will take into consideration already established face-to-face courses and workshops at regional and international meetings, and should also develop a web-based eLearning platform.

Aim 1: In 2017, the Task Force prepared a list of competencies as a foundation for the curriculum. The competency list was surveyed and approved by more than 800 ILAE members using the online evaluation Survey Monkey platform.

Aim 2: In 2017, the Task Force surveyed available teaching activities associated to ILAE either by weblinks, sponsored meetings or conferences. This survey identified 22 teaching activities, mostly targeted to an advanced audience of epileptologists.

Aim 3: We engaged a company specializing in curriculum development (ITPG) to develop a first common body of knowledge. Together with a subgroup of the Task Force, we specifically aimed to assign learning objectives to each competency. This common body of knowledge will be mandatory to further develop our program.

In 2018, we are planning to accomplish the common body of knowledge, and also organize ILAE's teaching program into 3 levels: Entry level A, intermediate level B, and advanced level C. Based on this curriculum, we will start developing a first eLearning pilot for level A using a problem-oriented eLearning approach. This work will require a project manager with professional experience in the arena of eLearning (to be hired) in order to coordinate the web-based teaching platform and acquisition of specific content for our target audience. The Task Force chose Latin America for the pilot program, to be extended later into other regions with lack of access to education in epileptology.

Ingmar Blümcke and Wei-Ping Liao
Co-Chairs, Epilepsy Education Task Force

EPILEPSY GUIDELINES TASK FORCE



Nathalie Jetté

Chair

Nathalie Jetté (Canada)

Members

Francesco Brigo (Italy)
Sanjaya Fernando (Sri Lanka)
Jackie French (USA)
Lara Jehi (USA)
Martin Kirkpatrick (UK)
Eva Kumlien (Sweden)
Katia Lin (Brazil)

MC Liaison

Samuel Wiebe (Canada)

The ILAE Epilepsy Guidelines Task Force led four meetings through 15/05/2018. A first ever meeting was held on Sunday September 3rd, at Barcelona, Spain during the International Epilepsy Congress. One telephone (13th November 2017) and two zoom video-tele conferences (18th December 2017 and 19th April 2018) were held after that.

Main tasks in progress:

- 1. Developed a Clinical Practice Guideline (CPG) workflow template** - This will make sure that we can track all CPG that are under development (under the patronage of ILAE) and to ensure that there are sufficient resources to support all said projects. In summary, the workflow template steps are as follows
 - a. The brief protocol would first be submitted to the CPG Task Force (CPG TF) by the interested group (e.g. ILAE TF or commission).
 - b. If approved by the CPG TF, then this would be presented to the ILAE Executive Committee (EC) for their approval.
 - c. Once approved by the EC, an email would go to ILAE chapter members to make sure there is not already a group working on developing this particular CPG. (This will minimise repetition of CPG work, and would save manpower and assets.)
 - d. The representative CPG TF member would primarily ensure that the method used by the working group adheres to the ILAE CPG TF toolkit.

A CPG Workflow template will also be sent to the chairs of TF/Commissions with the ILAE CPG development toolkit, etc.

2. CPG development toolkit webinar

The Chair, Jette, has a presentation ready for the webinar. This will allow ILAE members to look at it and learn about the CPG development toolkit, to enhance their knowledge on CPG development methodology.

3. Webpage on ILAE website with links to existing epilepsy guidelines and updated list of epilepsy guidelines on above website annually

The search strategy will be re-run from the last time it was done and a link to all CPG (or peer review journal where they are published) will be provided for each of them on the ILAE CPG TF webpage with the AGREE II quality scores listed. The search will then be updated once or twice a year and this will become a repository of epilepsy-related CPG.

4. Educational paper on “What is a guideline?” – N. Jette

We will work on developing this paper in the next 6-9 months and consider publication in *Epileptic Disorders* or *Epilepsia Open*. This would include an introduction into what a CPG is, benefits of having a CPG, the ILAE – CPG development process, and implementation of a CPG.

5. Test CPG development toolkit in high and low/middle income country

This will be further discussed in the future. This will require discussion regarding whether we start by taking an existing CPG and implement it in a low/middle income country and a high income country using the ADAPTE tool, or whether a new CPG is developed.

EPILEPSY GUIDELINES TASK FORCE *(continued)*

6. Develop implementation guidance for epilepsy guidelines in low/middle vs high income countries

We will work on developing some guidance on implementation strategies for epilepsy related CPG. M. Kirkpatrick will lead this work with help from the rest of the group. An implementation working group will be created to help with this task.

7. Collaboration with other groups (e.g. AES/AAN)

We have the opportunity to develop CPGs with other organizations, which everyone is supportive of. For example, the AAN/AES previously reached out to ILAE to see if these groups can collaborate on CPG development.

8. Methodologist

Consider collaborating with Cochrane Group for systematic reviews – to discuss further on our next call. This would be especially useful when we are doing the systematic review. We are also waiting to find out if our funding for a methodologist is approved.

9. Budget for ILAE – GTF 2018 - stipulated budget was discussed

10. CPG committee one day face-to-face meeting, possibly during the European Epilepsy Congress in August – 2018

Nathalie Jetté
Chair, Epilepsy Guidelines Task Force

GLOBAL OUTREACH TASK FORCE



Shichuo Li



Mary Secco



Alla Guekht

Chair

Shichuo Li, China (on behalf of the ILAE)
Mary Secco, Canada (on behalf of the IBE)

Members

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

Global Epilepsy Report and Global Epilepsy Survey

Our GOTF has been working with the WHO for the past 10 months to write a *Global Epilepsy Report*. The *Global Epilepsy Report* is a public health document that will tell the story of epilepsy globally. Our task force goal is to finalize and launch this 100-page report by October 2018. The report will be used in our meetings with policy makers and will be sent to Ministries of Health governments, epilepsy related social organizations, professionals, and the mass media.

To date, over 40 individuals representing the ILAE, IBE and WHO have been actively engaged in writing this report. The topics in the report include:

- Global epidemiology and impact
- Leadership, governance, policy, plans and programs for epilepsy
- Health care response to epilepsy
- Access to anti-epileptic medicines for epilepsy
- Misconceptions, stigmatization and discrimination around epilepsy and the social response to epilepsy
- Prevention of epilepsy
- Research on epilepsy
- Recommendations and Next Steps

The GOTF wishes to extend our gratitude to the individuals and chapters who completed the Global Epilepsy Survey. The data from the survey will be included in the *Global Epilepsy Report*.

World Health Assembly May 2018

Members of the GOTF attended the 71st World Health Assembly in Geneva in May 2018. Our objective was to meet with policy makers from member states around the world to highlight the epilepsy treatment and knowledge gap. In Geneva, our first advocacy event was on May 22nd where we co-hosted a two-hour lunch and panel with the theme: Calling to Global Action for Epilepsy. Approximately 80 attendees (World Health Organization staff, policy makers, NGO's, delegates from member states, UCB and other industry sponsors) attended the event. After lunch, our panel spoke about the burden of epilepsy on the family, the community and the healthcare system. Our unified message was to ask policy makers and the WHO to make epilepsy a public health priority with a sustained commitment towards implementation of the Epilepsy Resolution WHA 68.20.

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

The first country to speak on behalf of the Resolution was Russia. Russia had 3 core requests for the 194 member states:

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

Ministry of Health officials from Honduras, Zimbabwe and China also spoke in support and identified that we need to extend the reporting period on the Resolution as the work has not been completed. To achieve the three goals, we will require a collective response from ILAE and IBE chapters. Chapters should write their governments asking that the Epilepsy Resolution be included on the 144th Executive Board Meeting Agenda (January 24 – February 1, 2019).

Mary Secco,
Co-Chair, Global Outreach Task Force

JOINT ILAE/IFCN EEG DATABASE TASK FORCE



Sándor Beniczky

Chair

Sándor Beniczky (Denmark)

Members

Ingmar Blümcke (Germany)

Jean Gotman (Canada)

William Tatum (USA)

Elza Marcia Yacubian (Brazil)

Members IFCN

Christoph Michel (Switzerland)

Marcus Ng (Canada)

Pedro Valdes Sosa (Cuba)

Michel van Putten (Netherlands)

The International Federation of Clinical Neurophysiology (IFCN) and the ILAE have joined forces to develop an online interactive EEG database for education and research. The database will contain both raw data (de-identified video-EEG recordings) and features extracted and stored using the SCORE system (which was developed as an ILAE-IFCN collaboration). Distinct graphical user interfaces will be developed for educational and research functions. It would be an advantage to link the EEG database to neuroimaging and clinical databases.

A web-based, interactive educational database using the SCORE system, has been developed for the latest edition of the Niedermeyer EEG textbook. This includes 170 representative EEG/video-EEG samples, and will constitute a starting point for the future IFCN-ILAE database. Additional samples will be submitted by other members of the epilepsy and clinical neurophysiology communities. EEG case-reports submitted to Clinical Neurophysiology Practice will be uploaded to the database. A curriculum (items that need to be included into the educational EEG database) will be developed. The educational part of the database will be open access.

The objectives of the task force are to elaborate proposals on the structure and content of the database and overseeing its development. We expect to have the educational part fully functioning at the end of the term.

Sándor Beniczky,
Chair, Joint ILAE/IFCN EEG Database Task Force

NEXT GENERATION TASK FORCE



Helen Cross



Maeike Zijlmans

Co-Chair

J. Helen Cross (UK)

Maeike Zijlmans (Netherlands)

Members

Marian Galovic (UK), Chair, Young Epilepsy Section

Sheryl Haut (USA)

Premysl Jiruska (Czech Republic)

Christos Lisgaras (Greece)

Rosa Michaelis (Germany)

Genevieve Rayner (Australia)

The purpose of the Next Generation Task Force is to attract young people working in the field of epilepsy to the ILAE and lower the threshold for participation in ILAE activities.

The goals for this term were: 1) setting up a young epileptologists section, 2) aligning different activities that involve young epileptologists, such as the leadership program, mentor-mentee program, and young epileptologists section (YES), 3) supporting other task forces, such as the communication and topic-specific TF on next generation issues.

Strategy

1. Set up YES:
 - A) involve/attract all potentially interested people
 - B) organize a workshop to determine exact terms and form a core group during the workshop
 - C) further outreach (Twitter, Facebook, website, email lists, etc.)
 - D) organization of symposia and networking events during ILAE meetings
2. Bi-annual meeting of TF,

3. Create an outreach group for the ILAE from within YES

Accomplishments

1. The network is in the process of being set up, terms of reference have been agreed and a kick-off meeting will be held the weekend of 12-13 May in London. An email list has been created. A symposium will be held at the ILAE meeting in Vienna. Networking events will be organized at the meetings in Vienna, Bali and Bangkok.
2. We had a meeting at AES, a Skype meeting and we will meet in Vienna. A successful leadership program and mentor program was organized in Barcelona in 2017 and will be organized for Vienna in 2018.
3. Creating an outreach group will start during the kick-off meeting in London.

Proposed for next term (2018):

- 1 Set up the YES including web page, Facebook page, organizational structure, and core groups, inclusion of people from all parts of the world, future meetings, symposia, networking events, etc.
- 2 Bi-annual meetings, continuation of current programs. Alignment with young people initiatives, like the young neurobiologists. Including people from all continents.
- 3 Further creation of outreach group(s)/definition of their purposes.

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

NOSOLOGY AND DEFINITIONS TASK FORCE



Paolo Tinuper



Elaine Wirrell

Co-Chair

Paolo Tinuper (Italy)
Elaine Wirrell (USA)

Members

Edouard Hirsch (France)
Sameer Zuberi (UK), Past Chair

MC Liaison

Samuel Wiebe (Canada)

The Nosology and Definitions Task Force had its first meeting in Barcelona in Sept 2017. Our main goals are twofold:

- a. To propose a list of epilepsy syndromes and provide clear definitions for each syndrome
- b. To propose definitions and nosology for status epilepticus

The proposed definition of an epilepsy syndrome is "a characteristic cluster of clinical and laboratory features in an individual with epilepsy, often with etiologic, prognostic and treatment implications. These may have age-dependent presentations and specific co-morbidities."

We have identified four working groups, based on age at presentation, each of which is charged to propose a list of syndromes for inclusion, as well as clear definitions for each syndrome, building on the significant work already done for www.epilepsydiagnosis.org. The four groups are:

- a. Neonatal – S Zuberi, lead – to partner with Neonatal Seizures Task Force
- b. Infantile – R Nabbout, lead
- c. Childhood – N Specchio, lead
- d. Adolescent, Adult and Variable Age – E Hirsch, lead

Dr. E Trinka will lead the work on definitions and nosology of status epilepticus. This group will confirm working definitions for refractory SE, super-refractory SE, prolonged refractory SE and prolonged super-refractory SE. They will also address the terms NORSE and FRES.

Paolo Tinuper, Eugen Trinka, and Elaine Wirrell
Nosology and Definitions Task Force

YOUNG EPILEPSY SECTION



Marian Galovic

Chair

Marian Galovic (UK)

Members

Christos Lisgaras (Greece), Vice Chair
Katja Kobow (Germany), Treasurer
Genevieve Rayner (Australia), Secretary
Musa Watila (Nigeria), African Regional Representative
Mohmad Farooq Shaikh, (Malaysia) Asia and Oceania Regional Representative
Caroline Neuray (Austria), European Regional Representative
J. Sebastian Ortiz De la Rosa (Colombia), Latin American Regional Representative
Taylor Abel, North American Regional Representative
Neha Kaul (Australia)
Rosa Michaelis (Germany)

Following two successful networking events at the ECE 2016 in Prague and IEC 2017 in Barcelona, a new section representing young ILAE members was formed under the auspices of the ILAE Next Generation Task Force. This initiative was named the "ILAE Young Epilepsy Section (YES)."

To establish the organizational structure of YES, a kick-off workshop in London, UK was planned for May 2018. The planned goals of the workshop were to establish the aims of YES, define tasks and task forces, and stage a general assembly meeting to nominate representatives. YES members prepared Terms of Reference that were approved by the ILAE Executive Committee. Junior ILAE members younger than 40 years were invited to actively participate in YES

Marian Galovic
Chair, Young Epilepsy Section



ILAE
Regions
2017-2021



Angelina Kakooza-Mwesige

Chair

Angelina Kakooza-Mwesige (Uganda)

Treasurer

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

Education Officer

Jo Wilmshurst (South Africa)

Secretary General

Victor Sini (Cameroon)

Communications/Foster Research Agenda

Emmanuel Olatunde Sanya (Nigeria)

Raising Epilepsy Awareness/Increasing ILAE Membership

Edward Kija (Tanzania)

Access to Care/Link with the French-speaking countries

Ndeye Fatou Ndoeye

MC Liaison

J. Helen Cross (UK)

Commission Aims

Service Projects:

(a) Conducting training in epilepsy and strengthening the education activities of the CAA and will involve

conducting annual epilepsy training courses in either French, Portuguese or English-speaking countries in Africa, as well as organizing epilepsy training courses for hospital residents, nurses, and interns in Ethiopia and neighbouring areas. In addition, supporting the participation of African trainees in epilepsy distance learning courses by provision of bursaries.

(b) Improving the access to care for patients with Epilepsy in the region by provision of information on the Treatment Gap and the current epilepsy activities/situation on the continent, establishing a list, and updating the existing Drugs for Epilepsy in Africa and their cost on the African continent.

(c) Promotion of epilepsy awareness in the region by organizing regional epilepsy awareness campaigns in English and French speaking countries.

Research Projects:

Fostering epilepsy research in the region by determining the Epilepsy related research activities and needs on the continent, and encouraging collaborations within Africa and beyond.

Other Projects:

Multiply ILAE membership in the region by increasing the number of countries joining the ILAE on the continent.

Continuation of other CAA Projects:

These include the production of the bi-annual News E-Report "Epilepsy News Africa" and the organization of an African Epilepsy Congress (AEC) once every 2 years.

Angelina Kakooza-Mwesige
Chair, African Region

ILAE-ASIA OCEANIA



Akio IKEDA

Chair

Akio Ikeda (Japan)

Members

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

MC Liaison

Edward Bertram (USA)

The new four-year term of ILAE-Asia and Oceania began in September 2017, and has focused on continuity and further development. The aims of the ILAE-Asia and Oceania are to develop, stimulate and coordinate epileptology initiatives in the Asian and Oceanian regions. Based on it, 7 missions are listed as follows:

- 1) To advance and disseminate knowledge concerning the epilepsies throughout the Asian & Oceanian region.
- 2) To improve education and training in the field of the epilepsies in Asia via the activities of the Asian Epilepsy Academy (ASEPA).
- 3) To organize the Asian Oceanian Epilepsy Congresses together with the International Director of Meetings (IDM) and IBE's Regional Executive Committees.
- 4) To facilitate clinically relevant epilepsy research in Asia.

- 5) To serve as a link between ILAE, IBE, WHO and regional medical organizations to promote prevention, diagnosis, treatment, advocacy and care for all persons suffering from these disorders in the Asian and Oceanian region.
- 6) To promote the activities of local chapters, coordinate policies and administrative structures, and facilitate their involvement within the global ILAE agenda.
- 7) To review epilepsy services and the size of the treatment gap in each country, and aim to improve the former and reduce the latter.

Among the seven listed missions, ILAE-Asia and Oceania, and ASEPA have extensively worked on education which was associated with the successful continuation of AEPA-ASNA EEG board examination. On the other hand, as the other main arm of missions, clinically relevant epilepsy research has been gradually achieved despite several complicated reasons. Multi-institutional, international collaboration among ILAE-Asia and Oceania chapters with support by ILAE is very essential in the next four years for both education and research activities.

Akio Ikeda,
Chair, ILAE-Asia Oceania

ILAE-EASTERN MEDITERRANEAN



Chanez Triki

Chair

Chanez Triki (Tunisia)

Members & Officers

Ghaieb Aljandel (Iraq)
Abdulaziz Ashkanani (Kuwait)
Nihal El Shazly (UAE)
Hassan Hosny (Egypt), Past Chair
Boulenouar Mesraoua (Qatar)
Adel Misk (Palestine)
Reda Ouazzani (Morocco)

MC liaison

Emilio Perucca (Italy)

The ILAE-Eastern Mediterranean region was launched in 2004 and includes 14 countries from North Africa, Asia and the East side of the Mediterranean region.

Aims

The global objective of ILAE-Eastern Mediterranean is to improve the management of people with epilepsy. Region objectives:

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

Strategic Goals

The current East Mediterranean region had its first face-to-face meeting in January 2018. During this meeting, members of the board discussed the main needs and defined these strategic goals:

1. To collect data from the region
2. To promote epilepsy awareness
3. To conduct training in epilepsy and strengthen the educational activities in the region
4. To promote research activities in our region
5. To increase the membership from our region

Activities

To achieve these objectives, we have planned several activities:

- In order to create a good strategy, a SWOT analysis was necessary. Questionnaires were sent to the chapters for information on epileptic epidemiology in their country, the number of epileptologists, the number of courses and meetings on epilepsy.
- Set up a training program for primary care physicians, teachers, nurses and patients.
- In EMR, training on epilepsy is very limited, and in most countries it is limited to an annual congress. This is why we set up two epilepsy courses per year-one in English and one in French. For the year 2018, the English course was held in Cairo (Egypt) in January and the French course is scheduled for 18 to 20 October 2018 in Monastir (Tunisia).
- Also, we plan to attach ILAE-Eastern Mediterranean courses to the sub-regional congresses. We will have a course during the Pan Arab Congress of Neurology on September 2018.
- We also need to encourage web-based educational activities. Accordingly, CEMA endorsed the master's degree in epilepsy from the University of Sfax. This master's degree was launched in 2000, and since 2005 it has been an e-learning training. This master's course is in French, and we have plans to start classes in English in September 2018.
- In order to build a regional leadership, we set up a program of fellowships for young epileptologists, with a priority for the centers of the region. We are in the process of identifying level 3 and 4 epilepsy centers in our region. These fellowships will allow these young people to have advanced training in a particular field of epilepsy and to improve collaboration between the different countries of the region.

Chanez Triki
Chair, ILAE-Eastern Mediterranean

ILAE-LATIN AMERICA



Roberto Caraballo

Chair

Roberto Caraballo (Argentina)

Members & Officers

Patricio Abad (Ecuador)
Mario Alonso Vanegas (Mexico), Treasurer
Mario Camargo Villareal (Bolivia)
Fernando Cendes (Brazil)
Mabel Flores (El Salvador)
Lilia Morales Chacón (Cuba)
Marco Medina (Honduras), Past Chair
Juan Carlos Perez-Poveda (Colombia)

MC Liaison

Samuel Wiebe (Canada)

In the first period of this term, the following has been done to start working towards the goals proposed in Latin America in the areas of research, national programs, education, and meetings.

Fernando Cendes from Brazil has been appointed coordinator of the Research Commission of the Latin American Chapter. An important achievement in research is the establishment of a Latin American network to investigate the genetics of childhood epileptic encephalopathies in the region, under the leadership of Iscia Lopez Cendes from the Research Group at the Brazilian Institute of Neuroscience and Neurotechnology – BRAINN of the Campinas University, UNICAMP. In addition to the current 14 centers, new centers are being incorporated. Furthermore, after the use of cannabis for medicinal use was legalized in Argentina in 2017, the protocol for a trial in children with treatment-resistant epileptic encephalopathies was completed and approved by the authorities. The trial will start in July 2018.

Mario Camargo, from Bolivia, has been assigned as the coordinator of the commission on national programs. The task of the commission is to work with local governments on the development of epilepsy programs providing integrated and cost-effective care for people with epilepsy, as well as national laws on epilepsy to officially support these programs and to set up pilot projects. Considering the good experience with the pilot project successfully conducted in Bolivia, Paraguay and El Salvador have been selected to

start similar projects. On the other hand, Lilia Morales Chacón from Cuba will continue in charge of the commission on epilepsy in primary care.

Santiago Flesler from Argentina has been chosen as the representative of the Young Epilepsy Section (YES) in the region. He will be in charge of organizing teaching and research activities among the young people working in the field of epilepsy in Latin America.

In the province of Entre Rios, Argentina, the General Board of Education and the Provincial Ministry of Health have approved a program for a course on the management of epilepsy in primary schools. The course will be mandatory for teachers and personnel working in the setting of primary schools. Currently, the educational material, including a book on the management of epilepsy in the school setting, is being written. Plans are being made for dissemination of the program.

A Spanish-language master's degree in epilepsy is being developed. The preliminary program is ready and we are currently in the process of inviting the teachers. Feedback has been provided by Chahnez Triki, Chair of the Commission on Eastern Mediterranean Affairs, who already has a Master's in Epilepsy in place in French.

Three key papers are being translated into Spanish and Portuguese to make their contents available to non-English speaking colleagues in the region:

- Scheffer et al. ILAE Classification of the Epilepsies: Position paper of the ILAE Commission for Classification and Terminology;
- Fisher et al. Operational classification of seizure types by the International League Against Epilepsy: Position Paper of the ILAE Commission for Classification and Terminology; and
- Fisher et al. ILAE official report: A practical clinical definition of epilepsy.

Translation to Portuguese was done by Elza Marzia Yacubian, and the ALADE collaborated with the translation of the Operational classification of seizure types by the International League Against Epilepsy into Spanish.

ILAE-LATIN AMERICA *(continued)*

At the Trinidad and Tobago Meeting in March, PAHO, Caribbean Society of Epilepsy, the central ILAE and regional chapters of the ILAE, and the IBE made the decision to work on a diagnosis of the situation of epilepsy in the Caribbean. Based on this diagnosis, a collaborative effort for the development of epilepsy programs will be made. Additionally, in a meeting among representatives of the ILAE, IBE, and PAHO, discussing the current situation of epilepsy in Latin America, future activities in the region were planned, especially regarding the national programs.

The upcoming ALADE course will be held in Costa Rica during the 10th Latin American Congress on Epilepsy 2018, as is the custom.

Roberto Caraballo
Chair, ILAE-Latin America

ILAE-NORTH AMERICA



Nathalie Jetté

Chair

Nathalie Jetté (Canada)

Members

Amy Brooks-Kayal (USA)
Jorge Burneo (Canada)
Dave Clarke (Caribbean)
Sheryl Haut (USA), Past Chair
Jaideep Kapur (USA)
Karen Parko (USA), Treasurer

Ex-Officio:

David Corbin (Barbados)
Eileen Murray (USA), AES
Shlomo Shinnar (USA), AES

MC Liaison:

Samuel Wiebe (Canada)

Our goals and aims are aligned with the ILAE's emphasis on current and emerging knowledge on epilepsy prevention, diagnosis, treatment, research, and optimal comprehensive epilepsy care.

The Leadership Development Course, designed to train the next generation of ILAE leaders in essential skills, has been successfully held at the past two IEC meetings; the plan is for it now to occur annually, alternating between the IEC and a regional congress. A course will be held in August 2018 at the ECE meeting in Vienna and is being planned in coordination with the European Regional Commission.

We have established a Global Health Task Force to advance epilepsy education and care internationally. The first step is to identify ongoing global health outreach projects in epilepsy (educational and clinical) conducted by individuals within the North American region, and to create a repository of these projects to foster communication, collaboration and pooling of resources to maximize our global impact. Additionally, the task force will collect data on the design of successful projects, and also identify specific needs in various underserved regions to improve the design and impact of future projects.

The Pan American Health Organization (PAHO) Task Force is centred on strengthening the capacity of Caribbean countries to deliver evidence-based care to PWE within the framework of the PAHO Strategy and Plan of Action on Epilepsy. The TF aims to identify challenges and opportunities to improve access to care for PWE and to agree on key priorities for PAHO cooperation. This cooperation will address the significant healthcare disparities that exist across the English-speaking Caribbean region and the lack of advocacy and layperson involvement in most of the region.

In support of ongoing educational initiatives, we plan to provide funding in support of speakers to attend the Gordon Research Conference on Epilepsy and Neuronal Synchronization, and for an attendee at the San Servolo course on Epilepsies in childhood and adolescence: Diagnosis, management, evolution and transition to adult medical care.

The goal of the Harmonization of Regulatory Activities Task Force is to monitor key ongoing issues related to approval of antiepileptic drugs with regulators, including EMA, PMDA and possibly FDA. These include extrapolation of results in adults to children, use of AEDs in monotherapy, and shortening placebo exposure through time-to-event designs. A meeting will be held at the ECE in Vienna (Aug. 2018) with key task force members and regulators, followed by a symposium involving task force members and regulators.

Nathalie Jetté,
Chair, ILAE-North America



Topic-Oriented
Commissions
2017-2021

COMMISSION ON DIAGNOSTIC METHODS



Sarah Wilson

Chair

Sarah Wilson (Australia)

Members

Sallie Baxendale (UK)

Sándor Beniczky (Denmark)

Ingmar Blümcke (Germany), Past Chair

Jeffrey Britton (USA)

Paolo Federico (Canada)

Imad Najm (USA)

Sanjay Sisodiya (UK)

Jerzy Szaflarski (USA)

Vinayan K P (Kollencheri Puthenveetil)

MC Liaison

Samuel Wiebe (Canada)

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

In broad terms, the Commission seeks to identify key diagnostic methods for epilepsy, whilst ensuring there is a strong evidence-base for these diagnostic methods, and translating these identified methods into clinical practice. Working towards realising these broad objectives, there are six Task Forces, each focussed on a different domain, including: Neuropsychology, Imaging, EEG, Genes/Ontology, Autoimmunity/Inflammation, and FCD Classification.

In order to accomplish these goals, the Commission, through its Task Forces, will conduct systematic reviews, produce ILAE reports, ILAE clinical guidelines and toolkits, journal publications, and clinical recommendations for minimum standards or best-practices based on varying levels of evidence for the diagnostic methods of interest, as well as educational programs, symposia, teaching courses and the development of shared databases. The Commission's work will also rely on collaborative efforts together with other ILAE commissions to achieve its goals.

Sarah Wilson
Chair, Commission on Diagnostic Methods

COMMISSION ON EPIDEMIOLOGY



Charles Newton

Chair

Charles Newton (Kenya)

Members

Jakob Christianson (Denmark)

Jie Mu (China)

David Thurman (USA)

Ryan Wagner (South Africa)

MC Liaison

Sam Wiebe (Canada)

October 2017 to September 2018

The Commission has met on 6 occasions in the last 12 months:

- 13th October 2017 Skype call
- 3rd December 2017 Meeting at American Society of Epilepsy in Washington DC, USA
- 6th February 2018 Skype call
- 17th April 2018 Skype call
- 15th August 2018 Skype call
- 26th August 2018 Skype call at European Epilepsy meeting in Vienna, Austria.

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

1. Psychiatric Co-morbidity

Chairs: Dale Hesdorffer and Ruth Otterman

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

2. Injuries Task Force

Chair: Jie Mu

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

- a. Distinguish between injury 'due' to epilepsy and injury 'related' to epilepsy (e.g. if a patient has a skin rash due to taking AEDs, is this an injury?)

- b. Limiting the co-morbidities to be included (e.g. injury is not directly related to epilepsy, suicide and SUDEP)

- c. Differentiation between external/internal injuries

Registries Task Force

Chair: Jakob Christensen

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

- a. Database of Registries based upon work done by Nathalie Jette has been created
- b. Use data from the European Study of the Burden and Care of Epilepsy (ESBACE) (<http://www.epilepsyallianceeurope.org/programmes/esbace/>)
- c. Work on definitions of epilepsy to be used in registries:
 - I. Number of contacts with hospital (inpatient and/or outpatient), either 1 or 2 or more admissions.
 - II. Prescriptions of anti-seizure medication
- d. The Danish national hospital record was explored; the diagnosis of epilepsy (clinically) was used as the definition of epilepsy. Using 2 diagnoses increased the validity of the ICD 10 G40 diagnosis for epilepsy. Combination with information on reimbursement for anti-seizure drugs increased the validity further. Estimates were based on various definitions which will have an implication for estimates of burden of epilepsy.

Global Cost of Epilepsy Task Force

Chairs: Chuck Begley and Ryan Wagner

The aim of this task force is three-fold:

- a. To undertake a systematic review of the current literature on the global cost of epilepsy
 - I. A lot of work has been conducted as part of the Chapter for the ILAE/WHO/IBE Global Report for Epilepsy
 - II. This work is underway and databases and terms have been selected

COMMISSION ON EPIDEMIOLOGY *(continued)*

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

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

Treatment Gap Task Force

Chairs Natalie Jette and Arturo Carpio

The initial aims of this Task Force are to conduct

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

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

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

Global Burden of Disease Task Force

Chairs Charles Newton and Natalie Jette

The aim of this commission is to

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

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

Databases

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

Budget

The 2017 budget was used to support Ryan Wagner and Charles Newton's attendance at the meeting in Washington.

The 2018 budget will be used to support David Thurman and Ryan Wagner's travel to the meeting in Vienna.

David Thurman (Treasurer) will prepare a budget for the Thailand meeting.

- This will need include air travel for all members of the commission
- The Cost Task Force asked to have a separate, one-day meeting in Thailand

Charles Newton
Chair, Commission on Epidemiology

COMMISSION ON MEDICAL THERAPIES



Kimford Meador



Dong Zhou

Co-Chairs

Kimford Meador (USA)
Dong Zhou (China)

Members

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

MC Liaison

Emilio Perucca (Italy)

Access to Medicines & Treatment Gap

- 1) The Access to Medicine and Treatment Gap Task Force had a first Web Conference on October 27, 2017, where an initial work plan was presented and discussed. The proposed plan was to collect data from ILAE member countries on completed or ongoing strategies, projects and interventions to improve access to medicines to include initiatives on legislation, distribution and logistics, availability, pricing, quality control and prescribing regulations.
- 2) During the 2nd Web Conference on May 2, 2018, the majority of the TF members proposed and agreed to start collecting information on access to antiepileptic drugs in their respective countries and from neighboring countries in their own region in order to create a map relating to "access to medications." The survey would also aim to collect updated information on the availability and regulations on PB in different countries and identify existing or ongoing projects/strategies to improve access to antiepileptic drugs in different contexts. Though it would be very helpful to have a map of the full globe, it was suggested focusing the survey on countries designated as low- and middle-income countries (LMIC) where there is the greatest need in term of access to care and medication. This suggestion was based upon the Task Force's time, energy and resources.
- 3) A first draft of the questionnaire to be sent to health providers who deliver epilepsy care according to different countries and contexts has been created, and it will be soon finalized together with strategies of dissemination and data collection.

Botanicals & Traditional Medicines

The task force is working to expand its website with listings and a description of multiple botanicals. They are exploring information on traditional medicines.

Dietary Task Force

- 1) Dietary workshop is scheduled for 1st July 2018, the last day of AOEC in Bali, Indonesia, supported by ILAE.
- 2) Other dietary workshops are also done and planned this year in Myanmar in March, Bandung in Indonesia in July, Ulaanbaatar in Mongolia in August, and at least one of those workshops will be supported by ILAE.
- 3) The Strategic TF business meeting is scheduled on 4th, October, 2018, one day prior to the 6th Global Symposium on Ketogenic Therapies in Jeju, Korea, which is also approved by ILAE with financial support.
- 4) Jong Rho was joined by Eric Kossoff to prepare a revised consensus statement, being published in *Epilepsia Open*, which will provide a strong background for the use of the dietary therapy in an effective and safe manner.
- 5) Dietary TF is joined with the organizing committee of "The 6th Global Symposium on Ketogenic Therapy," from 5th to 9th October 2018, which is endorsed by ILAE. The anticipated attendance for this premiere biennial meeting is approximately 800 individuals from around the world.

Emergency Treatment

The task force continues work on producing two evidence-based guidelines: 1) European Guidelines in conjunction with the EAN and 2) Guidelines for resource-poor countries.

COMMISSION ON MEDICAL THERAPIES *(continued)*

Epilepsy in the Elderly

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

Generic Medications

- 1) A group has been working on the development of a manuscript that will serve as an informational and educational basis for understanding generic substitution. This manuscript will help provide a strong background of understanding on the concepts of generic substitution and issues faced in various parts of the world. Our hope is that the group will have a draft manuscript by the European Congress at the end of August 2018.
- 2) Another group has been working on the development of a survey to be sent to ILAE chapters and members. The survey is based on one that was developed by our South American colleagues, as they attempt to address issues of generic substitution in that part of the world. It is designed to help understand the challenges faced in various parts of the world, with the intent of guiding our task force as we developed final products.
- 3) The task force is planning to have a face-to-face meeting during the European Congress on Epileptology in Vienna, Austria.

Psychology

The Cochrane review on the impact of psychological treatments on HRQOL has been published in the Cochrane online library and a short version has been published in *Epilepsia*. The manuscript, "Psychological treatments for adults and children with epilepsy: Evidence-based recommendations by the ILAE Psychology Task Force", has been accepted

for publication in *Epilepsia* and will be published soon. Members of the Psychology TF will conduct the "Neuropsychology Teaching Course: Evidence-based psychobehavioral treatments for people with epilepsy" at the ECE. The next goal of the task force is the investigation of barriers to psychological treatment in PWE. We have drafted a survey which is currently circulated among members of the Psychiatry Commission to get their input. We will pilot the survey in Australia and we are about to submit the ethics proposal to conduct the survey.

Regulatory Affairs Task Force

As in previous years (European Congresses on Epilepsy in Stockholm 2014 and Prague 2016), we are organizing a session and a general discussion on the regulatory aspects of antiepileptic drug (AED) development during the next European Congress on Epilepsy in Vienna. The session will be attended by task force members, as well as members of the European Medicines Agency and Health Canada. Agenda items include: Revision of the EMA guidelines on AEDs, Extrapolation from adults to children (and from children to adults): What remains to be done (age range, seizure types, syndromes), New outcome measures: Time to event composite endpoints on seizures (frequency, severity, sleep or awake), composite endpoints on seizures and comorbidities, and choice of the endpoints (Trial population: Seizure types within a given syndrome or seizure type(s) across syndromes).

Women/Pregnancy

The Task Force has carried out a survey of available guidelines for the management of epilepsy in pregnancy in the ILAE Chapters. To date, 73 chapters have responded, and the results are currently being analyzed. The TF is currently working on a review on epilepsy and pregnancy intended for *Epileptic Disorders*. Drafts of some subsections have been written. This series of articles are also intended for adjustment to be suitable for publication on Wikipedia.

Kimford Meador and Dong Zhou
Co-Chairs, Commission on Medical Therapies

COMMISSION ON NEUROBIOLOGY



Aristeia Galanopoulou

Chair

Aristeia Galanopoulou (USA)

Members

Marco de Curtis (Italy, Past Chair)

Terence O'Brien (Australia)

Kathryn Davis (USA)

Marcio Moraes (Brazil)

MC Liaison

Ed 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 NBC and the chairs of its TF regularly, and also face-to-face meetings in the ECE at Barcelona 2017 and the AES meeting in DC (December 2017). The membership of the NBC TFs has since been finalized through discussions between the NBC chair and the elected TF chairs (see below for details). Through these common meetings, we have been trying to coordinate and synergize the activities of the various TFs and of the NBC. In addition, the following have been achieved and discussed:

1) Planning and organization of the NBC symposium in the ECE at Vienna 2018.

Topic: "Does coffee/caffeine consumption influence seizures and epilepsy?"

Date: August 26, 2018

Chairs: Astrid Nehlig and Aristeia Galanopoulou

Speakers:

- Detlev Boison (USA): "Mechanisms of action of caffeine in the brain and potential proconvulsant properties of caffeine"
- Astrid Nehlig (France): "Interindividual variability of caffeine metabolism and circulating levels"
- Christophe Bernard (France): "Consequences of early life caffeine exposure on brain development and susceptibility to seizures"
- Christian Samsonen (Norway): "Does coffee/caffeine consumption influence seizure activity in individuals with epilepsy?"

2) Planning and organization of the NBC symposium in the IEC in Thailand 2019.

Topic: "Biological rhythms that modulate the risk of seizures"

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

Chairs: Christophe Bernard and Aristeia Galanopoulou

Speakers:

- Maxime Baud (Switzerland): "Rhythms modulating seizure risk in human epilepsies"
- Philippa Karoly (Australia): "Circadian control of seizures and seizure forecasting"
- Christophe Bernard (France): "Circadian regulation in the pathophysiology and treatment of temporal lobe seizures"
- Judy Liu (USA): "Loss of CLOCK underlies focal epilepsies"

3) We have recommended for funding by NBC the following two workshops:

- Gordon research conference, "Mechanisms of epilepsy and neuronal synchronization" (August 2018), by Drs Bernard and Brooks-Kayal for the amount of \$11,000. The approved budget was \$6,000 for this meeting, since parallel funding would be provided by the North American Commission. The recommendation that workshop funding in the future would require ILAE participation in the topic selection was communicated to the organizers, per the ILAE EC decision. Further, the NBC recommendation was that funds should preferably go towards applicants from low-income countries and a report was requested at the conclusion of the meeting.
- 2nd Latin-American Workshop on Neurobiology of Epilepsy: "Cannabinoids and epilepsy, myths and realities". Organizer: Luisa Lilla Rocha Arrieta. Funding \$6,200 was recommended by the NBC and further approved by the ILAE EC. The same recommendations were communicated to the organizer. Further, we have revised the workshop application for funding to include the expectation that ILAE should be involved in topic selection of meetings for which support is requested.

COMMISSION ON NEUROBIOLOGY *(continued)*

- We also discussed that if a high-quality meeting application is submitted without this pre-requisite, NBC may consider instead to propose NBC-awarded funds for travel awards for applicants, which will be decided through the NBC and named as NBC Travel awards.

4) EARA (European Animal Research Association):

We have been approached by Kirk Leech from EARA with the invitation to have ILAE join EARA as a member, with an annual subscription of 12,000 Euros. EARA is one of the European organizations that has been advocating for the ethical use of animal experimentation and its benefit for progress in medical research. They were one of the leading opponents of the STOP Vivisection campaign, when ILAE and the NBC and Translational TF also opposed it, with a letter to the EU. They offer training and advocacy, and would be willing to include such sessions in ILAE conferences. I extensively discussed this issue with the NBC and TF chairs. The general feeling was that there is a benefit in associating with EARA, however the cost of the membership was deemed expensive, particularly since there are organizations that offer services for free (UAR: <http://www.understandinganimalresearch.org.uk/>). In a follow up email discussion with Kirk Leech, when I explained our willingness to collaborate and support the cause but hesitance in committing a membership fee, he reiterated that EARA would very much like to collaborate with ILAE and they would be willing to drop a one year membership to €7,000 Euros.

Ed volunteered to discuss this with ILAE and IBE and explore possibilities of making a statement supporting ethical animal experimentation in epilepsy research.

Budget: We have submitted a budget request for this year for \$15,000 for meetings of the NBC in Vienna and AES in 2018.

Planned face-to-face meetings: We are planning for a face-to-face meeting in Vienna (full day, August 26, 2018) and also at the AES meeting in New Orleans (date/time to be decided). ILAE representation is more than welcome at these meetings.

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 next one planned is for Thailand (June 2019).

The TF has been working closely with the local organizers (Drs Oranee Sanmaneechai and Kanitpong Phabphal) recommended by Dr Anannit Visudtibhan from the local chapter. In addition, we have been in contact with Richard Holmes, Denes McEvoy and Philippa Scott from the congress.

We went through a process of exploring different sites in Thailand within and outside of Bangkok and obtained several bids. We have selected to have the WONOE 2019 in Ayutthaya, at the Classic Kameo hotel, on June 16-20 2019. Richard Holmes and his group have volunteered to visit the hotel in June and advise us as to its suitability and the conditions of the contract, following which we will discuss the contract.

We have also discussed that we intend to change the format so that we make it like a workshop addressing a topic of high interest for epilepsy that needs a resolution or consensus, and less as a miniconference satellite to the IEC. A tentative topic is "What is a seizure?" which is likely to also cover different types of seizures.

Budget: There is a budget of \$40,744 which includes the carryover from previous years (funds from ILAE as well as the Harinarayan family), as well as an additional \$15,000 donated by UCB for the WONOE meeting, after discussions with Dr Sankar, who has been very effective in providing the Harinarayan and UCB funds for this purpose. This budget is expected to cover the deposit and final expenses for the site, as well as the Harinarayan Young Investigator awards.

We will require additional funds and we will seek sources once the site has been booked.

COMMISSION ON NEUROBIOLOGY *(continued)*

ILAE/AES Joint Translational TF

AES Co-Chairs

Aristea Galanopoulou (USA)
Greg Worrell (USA)
AES nominees (all USA)
Richard Staba
Anne Anderson
Manisha Patel
Kevin Kelly

ILAE co-chairs

Terence O'Brien (Australia)
Matthew Walker (UK)
ILAE nominees
Gunther Sperk (Austria)
Rudiger Koehling (Germany)
Teresa Ravizza (Italy)
Steven Petrou (Australia)

MC Liaison

Ed Bertram (USA)

Initiatives: We have had several zoom conferences to discuss the initiatives that our TF will undertake during the coming cycle. The following were agreed upon:

- (a) Continue the work of the TASK1 group with the following goals during the upcoming cycle:
 - TASK1-WG (working group) on classification of seizures and epilepsies in rodents.

We formed a steering committee to start addressing and formulating working groups (to be decided/invited) to complete the task. This will include:

- Classification and interpretation of abnormal and epileptic EEG patterns, and behavioral seizures. Eventually, this will also help the organization and will provide content for the Atlas of Rodent EEGs (see below).
- Working classification of rodent seizures and epilepsies in a manner that could translate to human seizures and epilepsies. In this effort, we will be considering EEG, seizure phenotype, comorbidities and other characteristics (pathology, imaging, genetics, etc).

- TASK1-WG for the creation of a public access online Atlas of Rodent EEGs. We formed a steering committee to organize this. We plan to create a WG consisting of individuals with technical expertise in website construction, as well as expertise in video-EEG studies to lead the process. We will plan to work also with both the ILAE (Dr Jean Gotman) and AES appointees to assist us in the process of building this website in a manner that could be accessible through both websites.

- (b) Continue the work of the TASK2 group, by extending the term of the existing TASK2 working group that aims to complete the systematic review of the animal epilepsy studies on outcome measures (led by Drs Simonato, Brooks-Kayal, Jensen).
- (c) Continue the work of the TASK3 group on preclinical common data elements (CDEs) in epilepsy by:
 - (i) expanding the topics of the CDEs (e.g., on pathology, omics, epilepsy phenotyping of animal models, imaging, etc.)
 - (ii) considering methods to make these tools accessible to most labs (e.g., software or databases)
 - (iii) undertaking efforts to disseminate the preclinical CDEs.

To achieve these, we plan to create sub-WGs to address each subtopic.

Continuation of activities from the previous cycle:

The following activities are currently underway/finalized from the past cycle:

- (a) Special issue on preclinical CDEs to be published in *Epilepsia Open* (TASK3): This is underway and the manuscripts have either been accepted or are under revision following the first reviews. We anticipate the finalization of the special issue over the next couple of months. We have planned to proceed into a request for community feedback following publication to further optimize these documents, which will be offered as open access.

COMMISSION ON NEUROBIOLOGY *(continued)*

- (b) TASK1-WG4 report on “How do we use in vitro models to understand epileptiform and ictal activity?” (Dulla, et al): The report has been approved by the TF and has been forwarded for approvals to both the AES and ILAE (decision pending).
- (c) TASK1 report on “Recording electrophysiological signals” (Williamson, et al): The manuscript is in the last stages of preparation. It has been reviewed by the TF and authors have been requested to revise before sending forward for AES/ILAE approvals. This is planned as a technical manual on electrodes.
- (d) We have received requests to offer the TASK3 preclinical epilepsy CDEs by CURE (Traumatic Brain Injury (TBI) initiative) and the TBI WG of the NINDS/Department of Defense. We have been collaborating with these groups on these requests.

Budget: We have submitted a budget request for this year to both AES and ILAE with matching fund requests. The ILAE budget request (\$15,000) has been approved tentatively, pending the AES decision and approval of an equal amount. We have requested an equal amount from AES towards the planned meetings and workshops (see below). We also plan to utilize the existing balance (carryover of \$27,814) towards planning the above initiatives (e.g., databases/software, website construction for the Atlas).

Planned face-to-face meetings: We are planning for a face-to-face meeting in Vienna (full day, August 25, 2018) and also at the AES meeting in New Orleans (date/time to be decided). ILAE representation is more than welcome to these meetings.

Genetics / Epigenetics Task Force

Chair

David Henshall (Ireland)

Members

Katsuhiko Yamakawa (Japan)
Albert Becker (Germany)
Chris Reid (Australia)
Alica Goldman (USA)
Erwin van Vliet (Netherlands)
Ischia Lopes-Cendes (Brazil)
Annapurna Poduri (USA)
Michael Johnson (UK)
Hela Mrabet (Tunisia)
Katja Kobow (Germany, liaison to Big Tata TF)
Steven Petrou (Australia, liaison to ILAE/AES JointTranslational TF).

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

Activities: The TF has proceeded to teleconferences to discuss the priorities and, specifically, manuscripts to prepare. Dr Petrou was proposed from the ILAE/AES Joint Translational TF as liaison to this TF to ensure that some of these activities will be in collaboration with the Translational TF, if the topic overlaps with the initiatives of the ILAE/AES Joint Translational TF.

COMMISSION ON NEUROBIOLOGY *(continued)*

Young Neurobiologists Task Force

Co-chairs

Premysl Jiruska (Czech Republic)
Stephanie Schorge (UK)

Members

Joseph Raimondo (South Africa)
Kathry Davis (USA)
Nigel Jones (Australia)
Liankun Ren (China)
Vadym Gnatkovsky (Italy)
Shilpa Kadam (USA)
Nihan Carcak (Turkey)

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 to best integrate the expertise of this TF with the initiatives and goals of the NBC and its TFs.

Activities: The TF has proceeded in zoom conferences to discuss next steps as well as discussions with the Next generation TF, Leadership, and YES society of the ILAE to coordinate and collaborate their initiatives. Actions decided include:

- Survey directed towards the young neurobiologists as well as established investigators to explore career opportunities and challenges for young neurobiologists.
- Create liaisons to other TFs: Vadym for the YNTF, Premek and Kathryn for the Leadership TF, Erwin for the Next Generation TF.
- Joint meetings with the TFs in Vienna.
- Website construction

Networks Task Force

Chair

Christophe Bernard (France)

Members

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

MC Liaison

Ed Bertram (USA)

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

COMMISSION ON NEUROBIOLOGY *(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)

MC Liaison

Ed Bertram (USA).

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

Activities: The advocacy TF along with the NBC will explore opportunities for collaboration with IBRO Global advocacy to build support for increasing resources and improving infrastructure for neurobiology epilepsy research. The advocacy TF will also advise and work with NBC on best ways of advocating for epilepsy research to the public, scientific organizations and policymakers.

Aristea Galanopoulou
Chair, Commission on Neurobiology

COMMISSION ON PEDIATRICS



Stéphane Auvin

Chair

Stéphane Auvin (France)

Members

Hans Hartmann (Germany)
Jo Wilmshurst (South Africa), Past Chair
Elissa Yozawitz (USA)

MC Liaison

J. Helen Cross (UK)

Task Forces

Neonatal Seizure Task Force

Hans Hartmann (Germany), Co-chair
Ronit Pressler (UK), Co-chair

Pediatric Psychiatric Issues

Colin Reilly (Sweden), Co-chair
Kette de Valente (Brazil), Co-chair

Research Advocacy

Pauline Samia (Kenya), Chair

Pharmacotherapy in Children

Lieven Lagae (Belgium), Chair

The ILAE commission on Pediatrics has selected four topics to work on: neonatal seizures, psychiatric issues in pediatric epilepsies, research advocacy in low/middle income countries and unmet needs in pediatric medical therapies of epilepsies.

The neonatal seizure Task Force continues the work on guidelines for neonatal seizure management which were initiated during last term. Our aim is to publish new ILAE guidelines. The group has been recruited in line with the Agree recommendations and the project is registered on Prospero. The literature search is completed and in the final stages of identifying studies for final inclusion. A satellite workshop of this task force will be organized during Vienna ECE meeting in August 2018 to report on progress on the guidelines and to provide education on this topic to a larger audience.

Following the work done during the previous term on comorbidities, the Commission on Pediatrics has a joint task force with the Commission on Psychiatry with the aim of providing clinical practice statements on diagnosis and management psychiatric issues in pediatric epilepsies and psychogenic non-epileptic seizures.

Since the start of the term, two papers have been finalized. One on advocacy has been accepted in *Epilepsia Open* (Wilmshurst, et al. Advocacy for children with epilepsy: Leveraging the WHA resolution. Advocacy Task Force, Commission of Pediatrics, International League Against Epilepsy. *Epilepsia Open* 2018). One from the comorbidities TF (Auvin, et al. Screening, diagnosis and management of ADHD in children with epilepsy. Consensus paper of the Task force on comorbidities of the ILAE pediatric commission, submitted) has been submitted to *Epilepsia*.

Stéphane Auvin,
Chair, Pediatrics Commission

COMMISSION ON PSYCHIATRY



Mike Kerr

Chair

Mike Kerr (UK)

Members

Rod Duncan (New Zealand)

Kousuke Kanemoto (Japan), Past Chair

Kette D. Valente (Brazil), Treasurer

MC Liaison

Alla Guekht (Russia)

The Commission on Psychiatry has started its new four-year term with a workplan designed to improve the psychiatric health and well-being of people with epilepsy by delivering guidance and education to clinicians in the field of epilepsy across the breadth of mental health. Our workplan is being developed by four Task Forces, each of which has a chair or co-chairs to lead the work of the group.

The Task Force on Identification Treatment and Prevention

chaired by Marco Mula, will provide recommendations about psychiatric interventions for major psychiatric disorders in the context of epilepsy, as well as to identify current knowledge gaps. The Task Force will focus on major psychiatric conditions that are epidemiologically or clinically relevant among adults with epilepsy, namely mood disorders, anxiety disorders and psychoses. Final outputs will include peer-reviewed documents based on systematic literature search, as well as expert consensus.

The Intellectual Disability Task Force, chaired by Christian Brandt, aims to develop standards in regard to diagnosis, pathways to investigation and treatment, including rescue medication. These are areas in need of improvement according to the White Paper issued by a previous task force. Within this broad field, the focus will be on diagnostics (especially genetics, psychology, and psychiatry) and rescue medication.

The Psychogenic Nonepileptic Seizure Task Force

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

The Task Force on Paediatric Psychiatric Issues

chaired by Kette Valente and Colin Reilly, represents a liaison between the joint task force of the Psychiatry and the Paediatric Commission. It aims to develop a consensus statement on the clinical assessment and treatment of common neuropsychiatric conditions in paediatric epilepsy. The task force also aims to develop a commission paper on the treatment of PNES in childhood.

Mike Kerr,
Chair

COMMISSION ON SURGICAL THERAPIES



Lara Jehi

Chair

Lara Jehi (USA)

Members

Guoming Luan (China)
Bertil Rydenhag (Sweden), Past Chair
Karl Rössler (Germany)

MC Liason

Samuel Wiebe (Canada)

Overview

The overall goal of the Commission is to examine the area of epilepsy surgery evaluation, implementation, risks, and outcomes to recommend how the League can help move forward, with a global perspective. This overall goal will be achieved through a group of five task forces, each focused on a specific challenge facing epilepsy surgery today. Each task force will be charged with the responsibility to provide proposed solutions or frameworks for solutions to address these challenges. This report outlines what these task forces are, and what their short- and long-term plans entail.

1. Task force for epilepsy surgery in the Resource-Poor Countries:

Chair: Mario Alonso

Epilepsy surgery remains an under-utilized treatment across the world. Resource poor countries face a particular set of challenges, including social (stigma, misconceptions, lack of support structures), financial (lack of health insurance coverage, challenging governmental resources, public health priorities), and logistical (lack of trained healthcare professionals, access problems) hurdles. This task force will work with the individual ILAE chapters in developing countries to: 1)- define the need and identify key challenges, 2)- propose “low hanging fruit” solutions (share “Best Practices” and develop educational opportunities, for example), and 3)- crystallize more complex needs into tangible ideas for incremental progress. Work performed by this task force will be coordinated with TF4 (evidence-based practice) and should include the collection of outcomes and safety measures.

Expected deliverables for a 4-year term:

- A. Short term:
 - i. Survey of outcomes, needs and key challenges
 - ii. Publication of recommended “Best Practices”

B. Long term:

- i. Establish infrastructure for systematic outcomes collection
- ii. Identify policy and other challenges for future progress.

Steps taken towards deliverables so far:

- A. October 2017: During their recent visit to Guatemala, Samuel Wiebe, President of the International League Against Epilepsy (ILAE), Mario Alonso-Vanegas, member of the commission for surgical therapies, and Lilia Nuñez, Vice-President for Latin America of the International Bureau for Epilepsy (IBE) participated in several events aimed at increasing the visibility of epilepsy as a global health issue. Especially noteworthy among these events was a meeting at the Republic of Guatemala Congress with the Health and Social Assistance Commission presided by Congresswoman Karla Martínez and the second legislative Vice-President, representative Eduardo Ramiro de Matta.
- B. December 2017: The task force voted to change its name from “Task force for epilepsy surgery in the Developing Countries” to “Task force for epilepsy surgery in the Resource Poor Countries”. This change was done to adequately reflect the scope of the task force.

2. Task force for epilepsy surgery education:

Chair: Stephen Schuele

Educational opportunities to improve the understanding and practice of epilepsy surgery should strive to bridge the gaps between evidence (data supporting surgery success), knowledge (awareness of this data among the medical community), and practice (referrals for surgery), taking into account local context and treatment availability. This task force will work with the ILAE Commission on Education to develop widely accessible and sustainable educational opportunities that take advantage of current distance learning tools while “building local capacity” for lasting impact. This group can also coordinate with the Guidelines Task Force to synchronize efforts on surgery-related guidelines, and facilitate dissemination of such guidelines as they become available. Educational products will include offerings pertaining to the technical aspects of neurosurgery for epilepsy, as well as education

COMMISSION ON SURGICAL THERAPIES *(continued)*

on indications, diagnosis, and prognosis. This group is encouraged to closely evaluate opportunities for telemedicine as it applies to epilepsy surgery.

Expected deliverables:

- A. Short term:
 - i. Develop content for online courses (VIREPA model) in coordination with the Education Commission
 - ii. Publish recommendations for telemedicine use in epilepsy surgery
 - iii. Paper on surgical techniques for major types of epilepsy surgery
- B. Long term:
 - i. Establish infrastructure for telemedicine use in context of ILAE (e.g. forum for online case discussions)

Steps taken towards deliverables so far:

- A. December 2017: An outline was defined for a paper that will discuss the basic principles of epilepsy surgery. The contents of the paper will provide the foundation for the contents of educational videos to be developed in coordination with the education task force. Pathways for publication of this material in print form will also be explored.
- B. Dr. Enrico Ghizoni, member of the task force, will participate in the upcoming eighth international pathology and epilepsy summer school in Erlangen (July 2018). He will perform dissections in the context of tutoring on epilepsy surgery principles. These dissections will be video taped and thus start the repository of online educational content provided by the task force.

3. Task force for pediatric epilepsy surgery:

Chair: Eliseu Paglioli

Children considered for epilepsy surgery represent a patient population with unique needs. Diagnostic considerations, treatment options, rehabilitation requirements, and functional outcomes differ at many levels from those of the adult population. This task force will focus on issues specific to pediatric epilepsy, building on accomplishments of the prior pediatric epilepsy surgery task force, and executing some of the identified areas of opportunities.

Expected deliverables:

- A. Short term:
 - i. Finish the papers started under the previous commission
 - ii. Organise a paediatrics epilepsy surgery technical meeting in relation to the next EEC in Vienna 2018 – in collaboration with other TF of the Surgical Commission
- B. Long term:
 - i. Find support to expand technical meetings to regional ILAE Congresses starting 2019
 - ii. Establish a framework to assess functional trade-offs in paediatric epilepsy surgery, collect data and provide a position paper by the end of the term
 - iii. Establish a framework to assess the impact of non-optimal surgical outcomes in children, collect data and provide a position paper by the end of the term
 - iv. Liaise with the Diagnostics and Genetics Commissions to begin an exploration of the impact of molecular diagnosis on surgical indications in children
 - v. Steps taken towards deliverables so far:
 - A. December 2017: At the American Epilepsy Society meeting, the members of the TF expressed their views on the proposed goals and were encouraged to review the pertinent literature and liaise locally in order to objectively advance ideas on how to move on and achieve the ultimate goals. The next meeting in Vienna will then be the kick-off of the concerted actions of the TF.

4. Task force for evidence-based practice of epilepsy surgery:

Chair: Dario Englot

Standards for the minimum technical, logistical, and manpower requirements to establish and grow an epilepsy surgery program are not clearly defined. Evidence clearly assessing the yield/value of many diagnostic interventions and surgical procedures is equally lacking. This task force is charged with:
1) - defining a clear set of standards to establish an effective epilepsy surgery program; 2)- defining the current level of evidence for the usefulness of tests used

COMMISSION ON SURGICAL THERAPIES *(continued)*

in pre-surgical evaluations; 3)- defining the current level of evidence for the effectiveness of existing and emerging surgical treatments. This task force will have a unique opportunity to delineate the “questions we need to answer” to ratify a scientific practice of epilepsy surgery.

Expected deliverables:

- A. Short term:
 - i. Systematic review and consensus recommendations coordinated with the Guidelines Commission
- B. Long term:
 - i. Establish framework for future “evidence” collection (registries, observational studies, etc.)

Steps taken towards deliverables so far:

- A. December 2017: At the American epilepsy Society meeting, it was decided the initial focus of the evidence-based task force would be to collect available evidence for the utility of presurgical diagnostic studies. The group is currently working on an outline for initial systematic reviews (one comprehensive review or multiple individual reviews) of PET, SPECT, and MEG/MSI in patients with lesional epilepsy. This is the major goal for the year, and will allow the task force to identify gaps of knowledge for future data collection.

5. Task force for Epilepsy Surgery Outcomes:

Chair: Lara Jehi

Standards for surgical outcomes reporting do not currently exist. This compromises transparency that patients and public health agencies are entitled to. Existing outcomes reporting scales focus exclusively on measuring postoperative seizure outcomes: This misses an opportunity to assess the full extent of this procedure on patients’ lives. The relationship between individual – often expensive and complex – presurgical evaluation tools and outcome remains unclear. This leads to a practice of expanding healthcare utilization based

on availability of tests, rather than a clear outcome definition. This task force will address the above three challenges (outcomes reporting standards, scope of outcomes measured, and evidence-based practice) in coordination with the Task force for Evidence Based Practice and the Task force on Education. The task force will endeavor to either build (or define the requirements to build) an infrastructure required to address these problems, either through randomized clinical trials or observational studies.

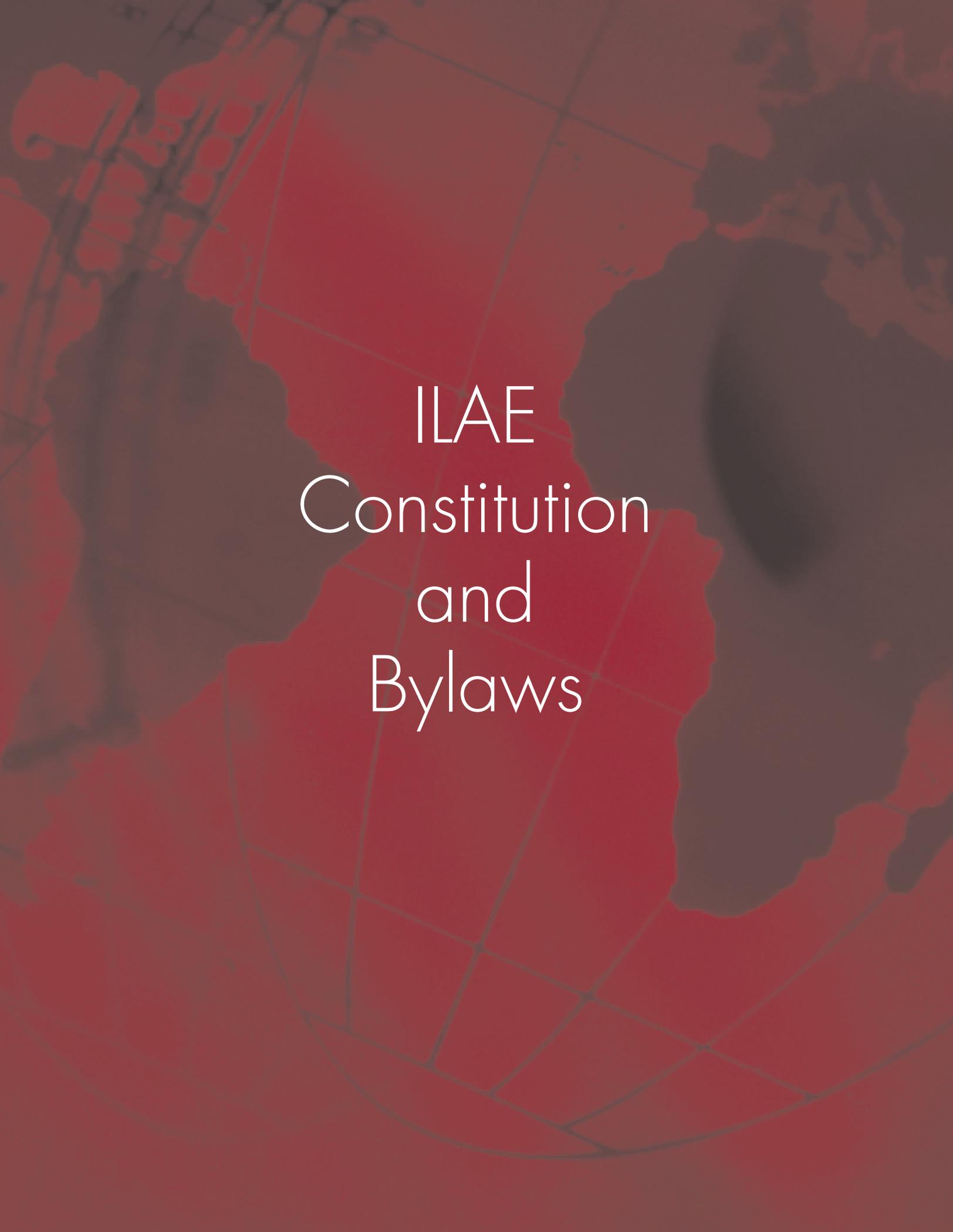
Expected deliverables:

- A. Short term:
 - i. Publish recommendations on outcomes reporting standards
 - ii. Publish reviews on epilepsy surgery outcomes beyond seizure-freedom
- B. Long term:
 - i. Establish an infrastructure for systematic outcomes collection
 - ii. Propose mechanisms for comprehensive outcomes assessment

Steps taken towards deliverables so far:

- A. Design a survey evaluating current standards of outcomes reporting in epilepsy surgery centers
- B. Plan a collaborative study on patient centered outcomes using the epilepsy surgery satisfaction questionnaire (ESSQ) once validated

Lara Jehi,
Chair



ILAE
Constitution
and
Bylaws

CONSTITUTION

Article I — Name

The name of this international organization, founded on 29 August 1909, in Budapest, is the International League Against Epilepsy (hereinafter called "the ILAE").

Article II — Effective Date

This Constitution is amended and valid as of 31 August 2011.

Article III — Objectives

The objectives of the ILAE are to:

1. Advance and disseminate throughout the world knowledge concerning the epilepsies.
2. Encourage research concerning the epilepsies.
3. Promote prevention, diagnosis, treatment, advocacy and care for all persons suffering from these disorders.
4. Improve education and training in the field of the epilepsies.

Article IV — Methods

To that end, but without restricting the main objectives of the ILAE, and insofar as the same shall be wholly charitable, the ILAE shall:

1. Encourage the establishment and maintenance worldwide of societies with the same objectives as the ILAE which will be members of the ILAE (hereinafter designated "Chapters").
2. Seek to establish and maintain effective cooperation with other organizations worldwide, active in the field of the medical sciences, public health, and social care, who are, or may become, concerned with problems related to the epilepsies.
3. Promote publications concerning the epilepsies and arrange for the publication of the journal of the ILAE, *Epilepsia*, and other ILAE educational and informational materials.
4. Organize or sponsor international Congresses, symposia, or other meetings, in particular the International Congress of the ILAE, to be held at the time and place as prescribed in the Bylaws.
5. Appoint special commissions or individuals for the purpose of studying specified problems related to the aims of the ILAE and making recommendations for implementation of specific activities.
6. Develop and apply other methods consistent with the objectives of the ILAE.

Article V — Legal Status

The ILAE is a non-profit, tax exempt, international organization incorporated in the District of Columbia, USA.

Article VI — Membership

1. Member Chapters are composed of professionals who are involved in patient care or research in epilepsy and whose primary concern is with the problems of epilepsy. The minimum membership of a Chapter is nine professionals which is deemed to be the minimum number that would allow the rotation of President, Secretary-General and Treasurer. Exceptionally, a Chapter may consist of a mixed professional and lay membership for a period of time. In this situation, only professional members constitute the basis for dues, voting, and holding

office. Chapters are autonomous societies, but their Constitutions and Bylaws must not contain articles inconsistent with the Constitution and Bylaws of the ILAE. A copy of the Chapter's Constitution and Bylaws must be kept in the League's main office. Any changes in the Chapter's Constitution and Bylaws must be submitted to the Executive Committee and the General Assembly.

2. There shall be only one Chapter in each country defined as any State recognized as a member of the United Nations and/or World Health Assembly. When there is more than one eligible organization in a country, the Executive Committee shall recommend for membership that organization which, in its opinion, can best accomplish the objectives of the ILAE. Organizations in territories/regions that do not fall within the above definition of a State, or in groups of two or more states, may exceptionally be considered for membership by the Executive Committee and ratified by the General Assembly.
3. The Chapters shall be voted into the ILAE upon the approval of the Executive Committee and two-thirds vote of those attending the meeting of the General Assembly. Pending approval by the General Assembly, a prospective chapter may be provisionally admitted to the ILAE by decision of the Executive Committee which will entitle the prospective chapter to all rights of membership except the right to vote.
4. By applying for membership a prospective chapter agrees to fulfill all obligations of Chapters as stated in this Constitution and Bylaws. The Chapter must submit to the Secretary-General a list of names and addresses of its own members. After a Chapter is approved, it must pay its annual dues.
5. A Chapter may withdraw from membership by giving notice in writing to the Secretary-General.
6. On recommendation of the Executive Committee, membership may be terminated by a two-thirds vote of those attending the meeting of the General Assembly, if the Chapter fails to pay its annual dues or if, for any other reason, it no longer fulfills the stated requirements for membership.
7. The Chapters are organized into Regions as determined by the Executive Committee.

Article VII — Governance

The ILAE shall be governed by the Executive Committee and the General Assembly.

Article VIII — The Executive Committee

1. The Executive Committee shall conduct the affairs of the ILAE subject to ratification by the General Assembly.
2. The Executive Committee shall consist of:
 - a. The President, Vice-President, Secretary-General, Treasurer, and the Immediate Past President, and the Chair of each of the recognized ILAE Regions as voting members. Within the Executive Committee, Regional Chairs will work on behalf of, and in the best interests of, the ILAE globally.
 - b. The President, Secretary-General, and Treasurer of the International Bureau for Epilepsy (hereinafter called the "IBE"), as Ex-Officio, non-voting members. (hereinafter called the "IBE"), as Ex-Officio, non-voting members.

- c. The Editor-in-Chief of *Epilepsia* as a non-voting member, appointed by the voting members of the Executive Committee.
3. The Management Committee:
- a. Shall consist of the President, Vice-President, Secretary-General, Treasurer, and Immediate Past President.
 - b. The Management Committee will implement the policies approved by the Executive Committee and govern the League between meetings of the Executive Committee.
 - c. The geographic distribution of the elected officers, including the President, shall be restricted as follows: Each of the newly elected Management Committee members must be primary members of different Chapters. Primary membership is defined by the location in which professional activities are performed. No more than two of the newly elected members of the Management Committee shall come from the same Region, as defined by the geographic Regions recognized by ILAE.
 - d. The President shall serve one term. Candidates for the Presidency must have served, or be in the process of serving, at least one term on the Executive Committee either as an elected or Ex-officio member. After serving as President, the person shall automatically serve one term as Immediate Past President.
 - e. The term of office for any Executive Committee member is four years. The members of the Executive Committee may be re-elected or re-appointed for one additional term to any of these offices. No member of the Executive Committee can serve more than two terms as an elected officer, unless elected as President. No person may occupy a seat on the Executive Committee for a period exceeding a maximum of sixteen years.
 - f. If the current President cannot fulfill the full term of office, a new President will be selected in accordance with the Bylaws. Should any vacancy in the Executive Committee occur, it shall be addressed by the Executive Committee subject to ratification by the General Assembly.
 - g. The President shall appoint an independent Elections Commission. The Elections Commission shall be chaired by the Immediate Past President. It will include one person from each of the recognized ILAE Regions and the Immediate Past Chair of the Elections Commission. The Executive Committee shall not interfere with the business of the Elections Commission. The Commission is to conduct the elections and establish appropriate procedures as described in the Bylaws and that are not in conflict with the Constitution.
 - h. The Executive Committee may hold meetings at any time or in any place which may be convenient to its members; it may conduct its business also by other appropriate means of communication. The business decisions of the Executive Committee, once taken, become effective, will be recorded in the minutes, and the minutes will be approved at the next meeting.
 - i. Two-thirds of the voting members of the Executive Committee constitute a quorum. Decisions are made by a majority of the voting members attending. In the event of a tie, the President has a deciding vote.
 - j. The Executive Committee shall have the power to formulate at any time Bylaws not in conflict with the Constitution. These Bylaws are legally binding, but a posteriori corrective action may be taken by the General Assembly to revoke or amend these rules.
 - k. The Executive Committee shall approve the annual budget of the ILAE and shall set the dues to be paid by the Chapters.

Article IX — The General Assembly

1. The General Assembly consists of all approved Chapters of the ILAE.
2. Regular meetings of the General Assembly shall be convened during each International Congress of the ILAE. Participants shall consist of one delegate from each Chapter who carries the total number of votes of that Chapter.
3. Representatives from more than fifty percent of the Chapters attending a meeting of the General Assembly shall constitute a quorum. Decisions will be taken by a majority of the votes of those attending.
4. The General Assembly shall receive and consider for vote of approval the reports of the President, the Secretary-General, and the Treasurer.
5. The General Assembly shall vote on proposals submitted by the Executive Committee.
6. The General Assembly shall approve the admission of new Chapters and the termination of membership of Chapters.
7. Meetings of the General Assembly are open unless a number exceeding ten percent of the delegates present requests to the Chair to close the meeting to observers. Only delegates may speak and vote. Exceptionally the presiding officer with the approval of the General Assembly may invite a non-delegate to speak, but not to vote.
8. Between regular meetings of the General Assembly, should urgent business arise requiring General Assembly action, this shall be carried out in writing, using available technology as determined by the Executive Committee. Such business must involve responses from at least fifty percent of the Chapters, and decisions would require a majority of the votes of those responding.
9. Chapters whose total votes correspond to a minimum of twenty-five percent of all available votes may request a written consultation by the General Assembly. Reasons for doing so must be sent to the Executive Committee ninety days before the consultation.

Article X — Finances

1. The ILAE shall have the authority to accept and administer gifts, legacies, movable or immovable properties, donations, and assets of any kind without any restrictions as to the amount or value and to collect annual dues of its Chapters.
2. The assets of the ILAE shall be used to further the objectives of the ILAE as authorized by the Executive Committee.
3. No portion of the assets of the ILAE shall be paid directly or indirectly to any Officer, members of its Commissions and Task Forces, or officers of its Chapters, except for payment of expenses made in the interest of the ILAE.

4. Proper books of account shall be overseen by the Treasurer and they shall be certified by a qualified auditor at the end of each fiscal year.

Article XI — *Epilepsia*

1. The Editor-in-Chief of *Epilepsia* shall be responsible for editing *Epilepsia* in accordance with the general policies established by the Executive Committee.
2. The Editorial Board shall consist of editors appointed by the Editor-in-Chief. The term of office of the editors is four years and editors may be reappointed for one additional term.
3. The editorial Advisory Board of *Epilepsia* shall consist of the Executive Committee and shall approve all contracts related to the publication of *Epilepsia*.
4. All financial responsibilities of *Epilepsia* reside with the Treasurer and the Executive Committee of the ILAE.

Article XII — Commissions and Task Forces

1. Commissions and Task Forces in unlimited number may be appointed by the President of the ILAE as recommended by the Executive Committee. The President, Secretary-General and Treasurer of the ILAE shall be Ex-Officio members of all Commissions and Task Forces, except the Elections Commission.
2. No expenses shall be incurred by a Commission or Task Force on behalf of the ILAE without the consent of the Executive Committee.
3. Annual budgets and financial reports of the Commissions and Task Forces must be approved by the Executive Committee.
4. Regional Commissions must have written rules of procedure that are in agreement with the League's Constitution and Bylaws. A copy must be kept in the League's Headquarters Office. Any changes in these rules must be submitted to the Executive Committee for ratification.

Article XIII — International Bureau for Epilepsy

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

Article XIV — Amendments

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

Article XV — Dissolution or Merger

1. The ILAE may be dissolved or merged with another body having similar objectives on proposal of the Executive Committee, ratified by two-thirds of the available votes of the General Assembly as well as two-thirds of the total number of Chapters.
2. In the event of dissolution, the assets of the ILAE may not be divided among its members but shall be transferred to one or more other international organizations of similar interests, as agreed by the General Assembly.

Approved August, 2011
Rome, Italy

BYLAWS

Ratified on October 02, 2011

Amended April 2012, June 2012, June 2013, May 2015, September 2016, March 2017

The Executive Committee is empowered by the Constitution (Article VIII-8) to establish Bylaws as necessary to achieve the objectives of the League, subject to their not being in conflict with the Constitution and to their ratification by the General Assembly.

The Secretary-General shall keep a book containing the current Bylaws, in which all modifications are entered as they are made.

Article I – Elections

1. Article 8.3.7 of the Constitution is interpreted to mean that the Elections Commission shall be chaired by the Immediate Past President of the League. The remainder of the Commission will include the immediate Past Chair and one representative appointed by the President from each of the League's geographical regions.
2. For each phase of the election, the Elections Commission shall ascertain if candidates are available and willing to serve. Candidates will provide the Elections Commission with appropriate background information on their candidacy. This information will be sent to each Chapter and publicized in the ILAE Website. Each candidate running for election must have the support of his or her respective chapter, but not necessarily nomination (when applicable) by his or her respective chapter.
3. Each Chapter has from 1-6 votes. The number of votes accorded to each Chapter shall depend on the number of professional dues paying members in that Chapter according to the most recent statement provided by the Chapter. The number of votes shall be determined by a sliding scale as follows:
 - up to 50 members: 1 vote
 - 51 – 150 members: 2 votes
 - 151 – 350 members: 3 votes
 - 351 – 750 members: 4 votes
 - 751 – 1500 members: 5 votes
 - above 1500 members: 6 votesChapters that do not collect dues shall have one vote.
4. All votes are secret. To ensure secrecy in all voting processes, the Elections Commission 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 Elections Commission. 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 Commission shall submit to the Chapters a list of persons fulfilling the requirements of the Constitution (Article VIII), who are available and willing to serve. Each candidate running for election must have the support of his or her respective chapter. The Elections Commission will ask each Chapter to vote for one of them by email or fax. If one of the candidates receives more than fifty percent of all possible weighted votes, this candidate shall be elected. If this is not the case, a runoff shall be held between the two candidates who received the highest number of weighted votes. The candidate in the runoff that receives the highest number of weighted votes cast shall be elected. If both candidates receive the same number of votes, the candidate with the highest number of un-weighted votes will prevail. If the tie still holds after counting un-weighted votes, the candidate who had been in the Executive Committee for 8 years already will prevail. In the event that the tie still holds, the older candidate will prevail.
6. Following completion of the Presidential Election, for the election of the three remaining positions of the Management Committee, the Elections Commission shall request each Chapter to submit a slate of five names from at least 3 different regions, without any ranking, as candidates for the remaining officer positions.
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 Commission shall choose a slate of fifteen candidates on the basis of non-weighted multiple nominations from the lists submitted by the Chapters. The slate must include candidates from at least 3 regions. The slate may be smaller if less than 15 people are nominated. The 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 Commission shall then submit the slate to each Chapter for voting by email, or fax. In this process, each chapter shall vote for five candidates from at least 3 different regions, without any ranking. The final votes for each candidate will be determined by the sum of the weighted votes received from all Chapters. If two or more candidates obtain the same number of weighted votes, the candidate(s) from the ILAE region(s) with the least representation among the

other elected officers will prevail. If a tie persists after consideration of regional representation, the candidate with the highest number of unweighted votes will prevail. If a tie still persists, the oldest candidate(s) will prevail.

10. The President-Elect with the advice of the Elections Commission 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 Commission will proceed with the elections for membership in each of the regional commissions as follows:

A. There should be eight voting members in each regional commission. These consist of five elected members (including the chair), the immediate past-chair (if not exceeding his or her 16 year limit of voting term), plus two members appointed by the ILAE President (in consultation with the newly elected chair). For regions with more than 35 chapters, an adjustment can be made with the addition of one more elected member, making a total of nine voting members. Each voting (elected or appointed) member, including the Chairperson, must be a primary member of a different chapter (not applicable to the immediate past-chair, or to non-voting/ex-officio members). In regions where an Education Academy exists or is developed, the regional commission appoints the Director of the Academy as a non-voting member.

B. Members hold office for a period of 4 years.

C. The Chair is elected first, followed by voting for the four (or five) elected members. Voting for the Chair and then other elected members is non-weighted (with each Chapter casting one vote for the Chair, and voting for each of the 4 [or 5] other elected members). To be eligible for election to Chair, an individual needs to have served on the regional commission as a voting (elected or appointed) or non-voting member for at least one term (4 years), but no more than two voting terms (8 years). Past Regional Chairs (appointed or elected) are not eligible for election to a second term. The Elections Commission on this basis will provide a list of all eligible candidates. Individuals on this list then need to agree to stand with the understanding that the Chair of the Regional Commission if elected, he/she will be a member of the Executive Committee and as such will be expected to provide thoughtful and prompt input on a large number of aspects related to the activities of the League. In addition, they will be asked to lead specific initiatives, to liaise with other groups, and to participate in annual budget reviews, which requires a substantial amount of work, in addition to active participation in regular Committee meetings by telephone or in person. Each candidate must have the support of his or her respective chapter. Chapters will then vote for a single candidate from this list in order to

elect the Chair by email, or fax. Each Chapter will cast one vote, supporting their preferred candidate on the ballot paper, or may abstain from voting. The candidate with the highest number of votes is successful. In the case of a tied ballot, a run-off election between the two tied candidates is held.

D. For election of other commission members, each Chapter may nominate up to three eligible candidates. Nominations are not compulsory- chapters may choose not to nominate a candidate or to nominate one, two or three candidates. Each person nominated by a single chapter must be from a different Chapter within the region. Persons from the Chapter of the newly elected Chairperson are ineligible for nomination because each voting member must be a primary member of a different Chapter. To be eligible for election, nominees should have served no more than 1 previous voting term on the regional commission. Unsuccessful candidates for the Chair may be nominated if they have not already served 2 voting terms and they are not from the same Chapter of the Chairperson-elect. A nominated candidate will require support of their own chapter, but not necessarily nomination by their own Chapter. The Elections Commission will assemble a full list of eligible nominations, and then from this list provide a slate of up to fifteen candidates on the basis of non-weighted multiple nominations as submitted by the Chapters. Individuals on this list need to agree to stand. If 15 or less nominations are received, then all nominated candidates will appear on the ballot. If several individuals are tied for 15th place, the nominee from the country least represented over the previous term, or if necessary the previous two terms of office, will be selected to stand for election.

E. Each Chapter may then cast one vote for each of the elected positions, voting for up to four (or 5) candidates on the ballot paper (dependent on number to be elected in that region) by email, or fax. Each region will determine whether a Chapter may choose to vote for less than the number of elected positions, and their vote still be valid, or whether a Chapter must vote for a minimum number of candidates in order for their vote to be valid. The decision made must be written into the regional election rules in advance of any election process, and clearly explained on ballot papers. The 4 (or 5, depending on the number of Chapters in the region as stated in item 1) candidates with the highest number of votes will be elected. In the case of a tied ballot, preference is given to candidates from Chapters that have had the least representation (accounting for all voting members,) over the previous term or, if necessary, the previous two terms of office. If this fails to break the tie, a run off vote will be carried out.

F. After the election of members is completed, the ILAE President, in consultation with the regional

Chairperson-elect, then appoints 2 additional voting members of the regional commission. These appointed members should have served no more than 1 previous voting term.

G. The North American Commission (NAC) requires different consideration as it only consists of three Chapters. For this reason, a special committee, named the Regional Selection Committee, will be created. It will consist of five members; one from each Chapter (each Chapter determining their own selection process), and the past two chairs of the NAC, as long as these individuals do not currently hold office on the ILAE Executive Committee, are not members of the Elections Commission and are not running for election. If no such person is available then the individual who has most recently served in the ILAE Executive Committee from the region (and is not a candidate) will be included. The Chair of the Selection Committee will be the immediate past NAC Chair. The role of the Regional Selection Committee is to create a Regional Commission by selecting the Chair and four elected members. The Commission will consist of 8 members including the 5 newly elected members, the past Chair and two members appointed by the ILAE president in consultation with the elected Chair.

- a. To be elected Chair, an individual needs to have served on the Regional Commission as a voting member for at least one term (4 years) and no more than two terms (8 years). The ILAE Elections Commission will provide to the NAC Regional Selection Committee the list of eligible candidates. Individuals on this list then need to agree to stand. Each nominated individual must have support of his or her respective chapter. Each member of the Regional Selection Committee will then vote for one candidate to elect the Commission Chair.
- b. Subsequently, to elect the remaining 4 members, each Chapter will propose up to 3 candidates for consideration from any Chapter in the region. Each nominated individual must have support of his or her respective Chapter, and should not have served more than one previous voting term on the regional commission. Based on the full list provided, each of the Regional Selection Committee members will vote for up to four candidates. At least one member of the NAC should be from each of the Chapters. In the event of a tie, there will be a run-off vote. The President of the ILAE will appoint two additional voting members to the Commission. This will make a total of 8 voting members including the past Chair.
- c. Role of the ILAE Elections Commission in the election process for the North American Commission:

- i. Notify the 3 chapters to nominate their representative to the Regional Selection Committee and determine their eligibility and willingness to serve. Identify the 2 past NAC Chairs eligible to be part of the Regional Selection Committee.
- ii. Approve the roster of the Regional Selection Committee according to the guidelines and meetings eligibility criteria.
- iii. Confirm the eligibility of the candidates for Chair of the Commission and for the other members of the Commission. The Regional Selection Committee will ensure that the nominees have agreed to run and notify the ILAE Elections Commission that this is indeed the case. Upon completion of the selection process, notify the ILAE Elections Commission which in turn will verify that the process was according to the written by-laws. Appointments to various positions within the Commission are decided by the Commission members based on their rules of procedure. It is recommended that Regional Commissions have education and information officers, and liaisons to global outreach and to neurobiology.
- iv. The election of the new members of the NAC will be completed at the same time as the other Regional Commissions.

Article II – Duties of Officers

1. The President serves as the chief elected officer of ILAE, and shall
 - A. Preside at meetings of the Executive and Management Committee and the meeting of the General Assembly;
 - B. Call regular and special meetings of the General Assembly, and conduct necessary mail ballots in accordance with guidelines outlined in the Constitution;
 - C. In conjunction with ILAE staff and Executive Committee members, prepare the agenda for the Executive Committee meetings;
 - D. Serve as a spokesperson for ILAE to the public, press, legislative bodies, and other related organizations;
 - E. After consultation with the other Executive Committee Officers, appoint the chairs and members of ILAE Commission and Task Forces, and outline their purposes and duties consistent with the ILAE strategic plan;
 - F. Serve as an ex officio member of all Commissions and Task Forces, except for the Election Commission;

- G. Promote active participation in ILAE activities, and report the activities of the Executive Committee and ILAE to the Chapters through E-mail broadcasts, the ILAE Website, *Epigraph* and other publications;
 - H. Serve as an ILAE representative on the IBE Executive Committee and maintain liaisons with other related organizations;
 - I. Monitor the activities, programs, and developments of ILAE, supporting and promoting policies and programs adopted by the Chapters, Executive Committee, and Commissions;
 - J. Provide the leadership for monitoring the ILAE strategic plan;
 - K. Recommend initiatives, research, and special assistance whenever necessary for Executive committee approval;
 - L. Assume a key role in the orientation and transition of the President-elect;
 - M. Identify, recruit and cultivate future leaders of the ILAE;
 - N. Assume other duties and responsibilities as may be assigned by the Executive Committee.
2. The Secretary-General ensures that records are maintained of all General Assembly and Executive Committee Meetings, and encourages chapter development. Specifically, the Secretary General shall:
- A. Serve as a member of the Executive and Management Committee;
 - B. Oversee the maintenance of the official records of ILAE including (i) minutes of regularly called meetings of the General Assembly and Executive Committee; (ii) affiliated Chapters in good standing; (iii) official correspondence to and from ILAE and other entities;
 - C. Maintain the Constitution and Bylaws, including responsibility for the process of amending the official documents;
 - D. Give timely notice of all meetings of the General Assembly and Executive Committee;
 - E. Conduct a roll call of the members at the meetings of the General Assembly and Executive Committee meetings, assuring that a quorum is present;
 - F. Promote chapter development and support activities; review applications and supporting documents for the establishment of new Chapters and provide guidance to the Executive Committee regarding the approval process;
- G. Serve as an ex officio ILAE representative on the IBE Executive Committee;
 - H. Represent ILAE with other associations or entities as assigned by the President or Executive Committee;
 - I. Receive, process and maintain the reports of Commission and Task Forces, submitting such reports to the Publication Task Force for review, with subsequent recommendation to the Executive Committee for approval for submission to *Epilepsia*, *Epilepsia Open* or *Epileptic Disorders*;
 - J. Oversee the publication of the Annual Report;
 - K. Perform such other duties and assume such responsibilities as may be assigned by the President or Executive Committee.
3. The Treasurer ensures the integrity of the fiscal affairs of ILAE. Specifically, the Treasurer shall:
- A. Serve as a member of the Executive and Management Committee;
 - B. Ensure that the ILAE accounts are maintained according to international accounting standards, assuring the financial integrity of ILAE;
 - C. Exercise prudence in maintaining the assets of ILAE;
 - D. Report on the financial condition of ILAE at the meeting of the General Assembly and the Executive Committee;
 - E. Submit the financial account of ILAE to an annual audit;
 - F. Working with the staff, develop the annual budget for review and approval by the Finance and Executive Committees;
 - G. Monitor the financial performance of ILAE in relation to the annual budget;
 - H. Ensure the timely payment of all ILAE financial obligations;
 - I. Oversee financial long-range planning;
 - J. Serve as an ex officio ILAE representative in the IBE Executive Committee;
 - K. Retain authority and responsibility for the financial activity of ILAE when such activities are delegated to staff or contracted with an external entity;
 - L. Perform such other duties and assume such responsibilities as may be assigned by the President or Executive Committee.

4. The Vice President will:
 - A. Serve as member of the Executive and Management Committee;
 - B. Assume the responsibilities of the President in his or her absence.
5. The Immediate Past President assists the President with guidance and advice based upon knowledge of previous Elections Commission policies and past practices. Specifically, the Immediate Past President shall:
 - A. Serve as a member of the Executive and Management Committee;
 - B. Serve as a Chair of the Elections Commission;
 - C. Provide advice and counsel to the President and act as an information source;
 - D. Assist in providing continuity between terms of office;
 - E. Perform such other duties and assume such responsibilities as may be assigned by the President or Executive Committee;
6. The Management Committee will meet as needed between meetings of the entire Executive Committee.
7. In case that a member of the Management Committee or the Executive Committee resigns or is unable to serve for the rest of the term the following procedures will be undertaken:

Management Committee: Should the President resign or is unable to serve for the rest of the term, the Vice President will step into this role. There will be then an election for a new Vice President following the procedures for worldwide elections and maintaining the regional requirements that pertain to the elected members of the Management Committee (article 1, item 7). Should a vacancy involve another member of the Management Committee (with exception of the position of Past-President), there will be an election for a new member following the procedures for world-wide elections and maintaining the regional requirements that pertain to the elected members of the Management Committee (article 1, item 7).

Executive Committee: Should a vacancy involve the positions of Regional Chair, an election will take place according to the rules for regional elections and approved by the EC. If such rules are not available at the time of the special election, the election procedures used for the 2013 elections will be followed.

8. The Editor(s)-in-Chief of *Epilepsia* shall be appointed by the Executive Committee and serve at its discretion, and conduct the day-to-day editorial business of *Epilepsia*. It may be appropriate for the Executive Committee to appoint more than one Editor-in-Chief of *Epilepsia*. The editorial content of *Epilepsia* is the responsibility of the Editor(s)-in-Chief.

Specifically, the Editor(s)-in-Chief of *Epilepsia* shall:

- A. Make the final decision on the acceptance or rejection of submitted manuscripts, including reports and documents produced by ILAE Commission and Task Forces and approved by the Executive Committee;
 - B. Make recommendations to the Executive Committee regarding number and role of Associate Editors and Managing Editor;
 - C. Appoint the associate/editors and the members of the Editorial Board, and supervise communication with the Board;
 - D. Call meetings of the Editorial Board as needed;
 - E. Recommend an annual budget for *Epilepsia* to the Executive Committee;
 - F. Liaise with the Publisher and oversee compliance with the contract;
 - G. Assist the Treasurer in supervising expenditures for the *Epilepsia* office
 - H. Perform other tasks as necessary for the operation of, and maintenance of quality, of the journal.
9. The Editor(s)-in-Chief of *Epilepsia Open* shall be appointed by the Executive Committee and serve at its discretion, and conduct the day-to-day editorial business of *Epilepsia Open*. It may be appropriate for the Executive Committee to appoint more than one Editor-in-Chief of *Epilepsia Open*. Currently, the Editor(s)-in-Chief of *Epilepsia Open* serves as an invitee non-voting member of the ILAE Executive Committee. Should the constitution be revised, it is recommended that the Editor(s)-in-Chief of *Epilepsia Open* be granted the same privileges and duties pertaining to the Editor(s)-in-Chief of *Epilepsia*.

The editorial content of *Epilepsia Open* is the responsibility of the Editor(s)-in-Chief. Specifically, the Editor(s)-in-Chief of *Epilepsia Open* shall:

- A. Make the final decision on the acceptance or rejection of submitted manuscripts, including reports and documents produced by ILAE Commission and Task Forces and approved by the Executive Committee;
- B. Make recommendations to the Executive regarding number and role of Associate Editors and Managing Editor;
- C. Appoint the associate/editors and the members of the editorial Board, and supervise communication with the Board;
- D. Call meetings of the Editorial Board as needed;
- E. Recommend an annual budget for *Epilepsia Open* to the Executive Committee;

- F. Liaise with the Publisher and oversee compliance with the contract;
 - G. Assist the Treasurer in supervising expenditures for the *Epilepsia Open* office;
 - H. Perform other tasks as necessary for the operation of, and maintenance of quality, of the journal
10. The Editor(s)-in-Chief of *Epileptic Disorders* shall be appointed by the Executive Committee and serve at its discretion, and conduct the day-to-day editorial business of *Epileptic Disorders*. It may be appropriate for the Executive committee to appoint more than one Editor-in-Chief of *Epileptic Disorders*. Currently, the Editor(s)-in-Chief of *Epileptic Disorders* serves as an invitee non-voting member of the ILAE Executive Committee. Should the constitution be revised, it is recommended that the Editor(s)-in-Chief of *Epileptic Disorders* be granted the same privileges and duties pertaining to the Editor(s)-in-Chief of *Epilepsia*.

The editorial content of *Epileptic Disorders* is the responsibility of the Editor(s)-in-Chief. Specifically, the Editor(s)-in-Chief of *Epileptic Disorders* shall:

- A. Make the final decision on the acceptance or rejection of submitted manuscripts, including reports and documents produced by ILAE Commission and Task Forces and approved by the Executive Committee;
 - B. Make the recommendations to the Executive Committee regarding number and role of Associate Editors and Managing Editor;
 - C. Appoint the Associate Editors and the members of the Editorial Board, and supervise communication with the Board;
 - D. Call meetings of the Editorial Board as needed;
 - E. Recommend an annual budget for *Epileptic Disorders* to the Executive Committee;
 - F. Liaise with the Publisher and oversee compliance with the contract;
 - G. Assist the Treasurer in supervising expenditures for the *Epileptic Disorders* office;
 - H. Perform other tasks as necessary for the operation of, and maintenance of quality, of the journal.
11. The President, Secretary General and Treasurer of IBE serve as ex-officio, non-voting members of the ILAE Executive Committee. Their function is to facilitate a close and collaborative understanding between IBE and ILAE.

Article III – General Assembly

The General Assembly is convened by the Secretary General and is chaired by the President. All members of the Executive Committee participate in the meeting of the General Assembly as non-voting members.

Unless otherwise indicated, matters brought before the General Assembly shall be decided by majority of the weighted vote of those attending an official meeting or responding to a mail ballot.

Article IV – *Epilepsia*, *Epilepsia Open* and *Epileptic Disorders*

Epilepsia, *Epilepsia Open* and *Epileptic Disorders* are the journals of the International League Against Epilepsy (ILAE).

Epilepsia publishes original articles on all aspects of epilepsy, clinical and experimental. The journal also publishes timely reviews, as well as commission and task force reports from various ILAE groups.

The mission of *Epilepsia Open* is to make original research on all aspects of epilepsy widely available through open access publication, and to give wider representation to the ILAE constituency.

Epilepsia Open also addresses the need to provide a publication forum for early, preliminary studies on epilepsy that may provide new directions for clinical and laboratory research including negative and confirmatory studies. *Epilepsia Open* also publishes Commission and Task Force reports from various ILAE groups.

The mission of *Epileptic Disorders* is to create educational links between epileptologists and other health professionals in clinical practice and scientists or physicians in research-based institutions. *Epileptic Disorders* also publishes commission and task force reports from various ILAE groups.

1. The Editorial Advisory Boards of *Epilepsia*, *Epilepsia Open* and *Epileptic Disorders* shall consist of all members of the Executive Committee, except for the Editor(s)-in-Chief. It advises the Editors on matters of general policies and arbitrate on matters referred to it by the Editor(s)-in-Chief, but shall leave the day-to-day conduct of the journal entirely to the Editor(s)-in-Chief and the Editorial Board. The editorial content of *Epilepsia*, *Epilepsia Open* and *Epileptic Disorders* is the responsibility of the respective Editor(s)-in-Chief.
2. The Executive Committee shall approve or terminate any contract with the publisher(s). It shall determine the budget of the journals.
3. The Editor(s)-in-Chief will take all steps necessary to fulfil the aims of ILAE as it pertains to the mission of the journals.
4. The responsibilities of the Editor(s)-in-Chief are described in Article II.7 of the Bylaws.

Article V – Resource- and Topic-specific Commissions and Task Force

1. Each Resource- and Topic-oriented Commission and Task Force shall have a Chair appointed by the President in discussion with the Executive Committee. Each Commission shall designate a Secretary, Treasurer, information officer, and representative to the Global Outreach activities.

If appropriate, the Commission should appoint a liaison to the Neurobiology Commission. Liaisons to other Commissions are encouraged. The President will appoint one member of the Executive Committee as the primary contact who serves as an ex-officio member.

2. Funds raised by an individual Commission, when not spent within the next fiscal year, may be allocated to the same commission for the subsequent fiscal year, subject to the commission providing a plan for the utilization of the funds and approval of the plan by the Executive Committee. At the end of the term of each Commission, any unused funds will be incorporated into the general ILAE assets.
3. The term of office of each Commission shall expire within six months of the end of the term of the Executive Committee to complete unfinished business. It is recommended that the outgoing Chair(s) be involved in the generation of the revised Strategic Plan for the new Presidential term. No member of the Commission can serve for more than two terms, unless he/she is elected as Chair after having completed two terms.
4. Task Forces are appointed for specific purposes and their term of office expires when their duties are completed.
5. The Chair of each Commission and Task Force shall make interim reports and recommendations to the Executive Committee as deemed necessary and shall submit a final report at the conclusion of their term.

Article VI – Chapters’ Obligations

1. Chapters shall be open for membership to all professionals working for epilepsy in that country, territory or region as defined in the Constitution.
2. Each Chapter must send to the ILAE Secretary-General the names and contact information of its officers within thirty days after the Chapter’s General Assembly Meeting during which a new Executive Committee takes office. If changes in contact addresses occur, these must be immediately reported to the Secretary General of the ILAE.
3. Within thirty days after each Chapter’s General Assembly meeting, the Chapter must submit any changes to its Constitution and Bylaws (in English) to the Secretary General.
4. By March of each year, every Chapter is requested to upload/enter their database, including e-mail addresses of elected officers, to the ILAE website.
5. Before October 1 of each year, each Chapter shall pay to ILAE, annual dues which shall be proportional to the number of dues paying members as of December 31 of the previous year, and shall be fixed for each fiscal period of the General Assembly. Dues for a Chapter are 3% of the annual dues that the Chapter charges each member, multiplied by the number of Chapter members, or a minimum payment of \$10 (U.S.)

whichever is highest. In countries where exchange regulations do not allow for remittance of funds outside the country, then Escrow accounts may be established with the approval of the ILAE Treasurer.

6. If a Chapter without consent of the Executive Committee omits paying its dues, it will be once invited to do so, if the next year, dues are again not paid, the Executive Committee may propose disaffiliation to the General Assembly in writing and/or have its right to vote at the meeting of the General Assembly revoked. Two thirds of votes cast (with at least two thirds of all available votes having been cast) have to confirm disaffiliation.

Article VIII – Fiscal Year

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

Article VIII – Staff

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

Article IX – Meetings

1. The International Congress of ILAE shall be held ordinarily every two years, in conjunction with the International Bureau for Epilepsy.
2. In the year between two International Congresses of the ILAE, the Regional Divisions of the ILAE will organize Regional Congresses with the support of the ILAE.
3. The International Congress of ILAE and the Regional ILAE Congresses will be organized with the assistance of the ILAE-designated International Director of Meetings.
4. The ILAE may sponsor or support, wholly or in part, other meetings relevant.

Article X – Endorsement of guidelines

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

Article XI – Regions

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

4. Regional Commissions can have designated funds which they access via the budget process.
5. Regional Commissions should coordinate local educational activities.
6. Regional Commissions should run their congresses under the direction of the International Director of Meetings.
7. Regional Commissions should review epilepsy services and the size of the treatment gap in each country and aim to improve the former and reduce the latter.
8. Regional Commissions should develop documents with the aim of stimulating local medicopolitical initiatives and improving patient care.
9. Chapters can belong to only one region.
8. A quorum for a JEC shall be the presence of a majority of the members of each of the ILAE and IBE Executive Committees.
9. A JEC may be convened at any time mutually acceptable to the Presidents of both the ILAE and IBE.
10. To be considered by a JEC, a motion must be moved by a member of one Executive Committee, and seconded by a member of the other.
11. Responsibility for administration, minuting etc. of JECs shall be shared equally between the Secretaries General of the ILAE and IBE, in a manner acceptable to both.
12. Responsibility for overseeing all financial matters considered by JECs shall be shared equally between the Treasurers of the ILAE and IBE, in a manner acceptable to both.

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

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

13. A Joint Committee, consisting of the voting members of the ILAE Executive Committees and the Management Committee of IBE, is authorized to take actions in the name of a JEC between JEC meetings.

Such actions must:

- A. Be approved by a majority of each of the Committees of the ILAE and IBE;
- B. Be in accord with policies of both the ILAE and IBE;
- C. Involve neither Executive Committee in expenditure exceeding a sum to be set by each Executive Committee;
- D. Be notified to each Executive Committee as soon as possible;
- E. Be ratified by each Executive Committee at its next meeting.

Article XIII – Indemnification

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

Article XIII – Amendments

The Executive Committee shall have the power to amend these Bylaws by the affirmative vote of a majority of the voting Executive Committee members then in office.

OUR VISION

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

OUR MISSION

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