

# On the Horizon

## 2013 ANNUAL REPORT





# OUR VISION

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

# OUR MISSION

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

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# EXECUTIVE COMMITTEE

## 2009-2013

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**SECRETARY-GENERAL**

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Calgary, AB, Canada

**TREASURER**

Emilio Perucca, MD, PhD  
Pavia, Italy

**PAST PRESIDENT**

Prof Peter Wolf  
Copenhagen, Denmark

**FIRST VICE PRESIDENT**

Tatsuya Tanaka, MD  
Asahikawa, Japan

**SECOND VICE PRESIDENT**

Michel Baulac, MD  
Paris, France

**THIRD VICE PRESIDENT**

Marco T Medina, MD  
Tegucigalpa, Honduras

**EDITOR-IN-CHIEF, *EPILEPSIA***

Philip A Schwartzkroin, PhD  
Davis, CA, USA

**EDITOR-IN-CHIEF, *EPILEPSIA***

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Dublin, Ireland

**IBE, SECRETARY-GENERAL (EX-OFFICIO)**

Prof Carlos Acevedo  
Santiago de Chile, Chile

**IBE, TREASURER (EX-OFFICIO)**

Grace Tan  
Singapore

# PRESIDENT'S REPORT



Soloman "Nico"  
Moshé



Emilio Perucca

Allow me to extend my gratitude for your personal commitment and contributions to the League over the last four years. The achievements of the 2009-2013 term were the result of so many like yourself who stepped forward to give time, effort and expertise to help fulfill the League's mission. It has been my great privilege to work with you towards a world where no person's life is limited by epilepsy. I look forward to continuing in our joint efforts for many more years to come.

Soloman Moshé  
*President*

## A MESSAGE FROM THE PRESIDENT-ELECT

It is a great honor to have been elected as the League's president for the 2013-2017 term. I wish to express my deep gratitude to all the Chapters and individuals that endorsed my candidacy. Their support reinforces my commitment to serve our constituency to the best of my efforts and capabilities.

Since its founding in 1909, ILAE has worked tirelessly to improve epilepsy care all over the world. Through teamwork, we have advanced our historical roles in education, training and research, disseminated knowledge with our Congresses and prestigious journal *Epilepsia* (now joined by *Epileptic Disorders*, which takes up the role of educational journal of the League), and spear-headed novel ventures with our partners — such as WHO and IBE. As a result, ILAE is recognized as the leading society of medical professionals devoted to improving the lives of persons with epilepsy.

It is my view that in the coming years we will have an unprecedented opportunity to advance our mission more than ever before. My specific priorities as ILAE president will include:

1. **Access to Care.** The majority of people with epilepsy live in the poorest regions of the world and have little access to a sustainable supply of medications. The League has the duty to address this unacceptable treatment gap and I will therefore make this a major focus of my presidency. This will have many components, including public outreach, education, ensuring availability and distribution of medications, and support for the development of Centers of Excellence in Epilepsy Care. Sustainability will be a prerequisite and all stakeholders, starting with local

Chapters and governments, must be involved. I am aware of the difficulties, but I believe we can make major advances using the experience acquired in successful initiatives, such as those conducted in China and Brazil in partnership with local Chapters, IBE and WHO.

2. **Promote optimal epilepsy care worldwide.** This initiative parallels Access to Care. With 15,000 members in 109 Chapters, we are in a unique global position to impact government policies addressing epilepsy care. Having been personally involved in the approval of the European Declaration of Epilepsy, I appreciate the tremendous potential that we and our partners have in influencing the political agenda for the good of people with epilepsy. Similar initiatives have flourished in the Americas through the Pan American Health Organization Action Plan for Epilepsy and in the United States through the Institute of Medicine Report. I see opportunities in other regions of the world. We must build on existing momentum to motivate governments to take concrete actions for epilepsy care. To achieve this goal, ILAE will work closely with WHO, our Regional Commissions, Chapters and like-minded public partners.
3. **Advance knowledge on epilepsy.** Epilepsy research is grossly underfunded. We will miss no opportunity to emphasize the need to allocate greater resources for epilepsy research from governments and private institutions. The ILAE contributes to advances in epilepsy knowledge through its network of Commissions and Task Forces. These activities will be refined and coordinated to support our Strategic Plan. I will also ask Commissions to help us with another important mission, i.e., the identification and mentoring of the next generation of leading epileptologists.
4. **Education.** No improvement in epilepsy care can be achieved without an adequate supply of epilepsy professionals. Education remains a major focus of the League's mission. We currently sponsor a wide array of activities, including congresses, courses, summer schools, workshops, distance education programs, fellowships and visiting professorships. These activities need to be appraised to enhance their merit, improve their cost-effectiveness and identify areas for more effective dissemination. This may include the broadening of our publication and web platforms. Educational activities must be adapted to local needs and cultures, and our Regional Commissions and Chapters should be involved closely in this process. The ILAE Regional

# PRESIDENT'S REPORT *(continued)*

Commissions contributed greatly to educational programs over the years, and I look forward to similar advances for our youngest Region, Africa, through our newly formed African Commission.

5. **Protect the League's long-term financial viability.** To maintain and expand our activities, long-term financial sustainability is essential. In the last few years, the Executive Committee took effective action to reduce administrative costs, increase revenues and diversify investments. However, there is no room for complacency. Our sources of income from congresses and publications are under continuous threat, and the next Executive Committee must be vigilant and prepared to work with new paradigms to adjust to the ongoing changes.

I very much look forward to working together with the next Executive Committee, our Chapters, the IBE and all our members toward achieving these goals. A crucial component of teamwork is communication — I encourage everyone to feel free to contact me and contribute ideas and suggestions as we develop the agenda of the League for the next term.

I look forward to working together towards the fulfilling of our vision — a world in which no person's life is limited by epilepsy.

Emilio Perucca  
*Treasurer and President-Elect*



# TREASURER'S REPORT



Emilio Perucca

The League has an ambitious agenda for the years ahead and appreciable resources are needed to maintain and expand our activities. In last year's Annual Report, I described in detail the many steps which were taken during the 2009-2013 term to strengthen the financial viability of the organization.

In agreement with the recommendations of the Strategic Plan, we streamlined the ILAE administrative structure and we improved its operational practice to ensure an efficient and effective management. On the expense side, we were able to reduce administrative costs and to increase significantly the support to our Commissions and Task Forces. Support to a wide range of educational activities, including the distance education program (VIREPA), was also expanded. Transparency and efficiency in allocating resources to different activities were improved through the creation of an external Budget Review Task Force, which has since been in charge of evaluating proposals submitted by Commissions and Task Forces and liaising with the Executive Committee in setting priorities for appropriate funding.

Income from *Epilepsia* has been secured through a five-year contract with Wiley-Blackwell guaranteeing annual increases in revenue for the League over the period 2011-2015. In 2013, this contract was extended for an additional year to permit a synergism between Wiley-Blackwell and John Libbey in the distribution of our newly acquired journal, *Epileptic Disorders*, which will function as our educational journal.

Income to the League from congresses has shown a clear declining trend in recent years, largely as a result of reduced sponsorship from industry. This development was not unexpected, and justifies the efforts that the League has made over the years to secure a level of reserves sufficient to permit optimal functioning in a less favorable financial environment. In such a climate, it is essential for the League to implement a carefully balanced investment policy and to monitor the portfolio's performance. This has been made possible by the creation of a Finance Advisory Subcommittee consisting of volunteer professionals with top level expertise in financial matters. The assistance of our advisors has been critical in developing an appropriate benchmark to gauge the performance of our investments, and in interacting with our investment firm to ensure optimal diversification of our portfolio. I am also pleased to report that all members of the Finance Advisory Subcommittee have agreed to continue to provide their services into the next term.

Because of the actions described above, coupled with the favorable growth of most major markets in recent years, the finances of the ILAE have steadily improved during the last five years. Our total assets have increased from \$12,599,904 on December 31, 2008 to \$17,147,563 (non-audited estimate) on October 31, 2013 (Figure 1).

Figure 1: ILAE Total Assets 2008-2013

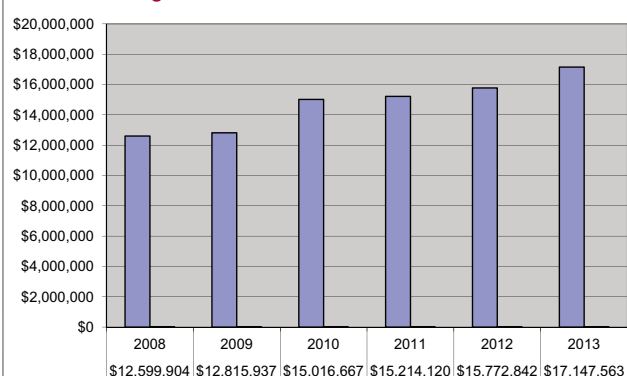
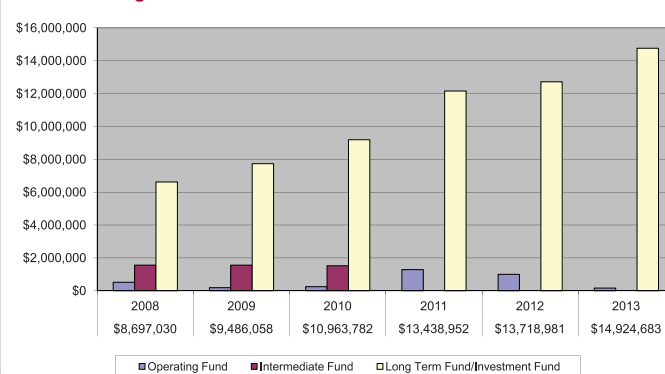


Figure 2: ILAE Investment Portfolio 2008-2013



Likewise, our investment portfolio has increased in the same period from \$8,697,030 to \$14,924,683 (Figure 2).

There has been considerable debate within the Executive Committee and our constituency at large on the wisdom of allocating part of our yearly surplus to build up our reserves. We feel this policy is justified for a limited time period until our reserves have reached about \$20 million, a target which we hope we will be able to achieve by 2018 to 2020. This is the critical level of reserves which, in agreement with estimates confirmed by our advisors, should generate sufficient annual returns from investments in the long-term to sustain our activities without having to draw steadily on our assets. This will allow the League to continue its many projects and initiatives in the face of declining support to congresses from the pharmaceutical industry (a scenario that has already materialized) and of potentially lower publication revenue due to the expanding open access movement. It should be stressed that our strategy aimed at increasing our reserves to a predefined level has not implied, and will not imply, a reduction in investments into our activities. On the contrary, thanks to a reduction of operational expenses and healthy returns from investments, over

# TREASURER'S REPORT (continued)

the last term we have been able to actually increase the budgets allocated to our Commissions, Task Forces and distance education programs.

As shown in Figure 3, 2012 was an exceptionally favorable year for the League's finances due to robust return from investments, which made up 39% of the overall revenue. Because of the terms negotiated with *Epilepsia's* publisher, returns from publications have remained at a healthy level, whereas the trend towards a decreasing surplus from congresses is clearly continuing.

**Figure 3. Breakdown of Revenue and Expenses for 2012.**

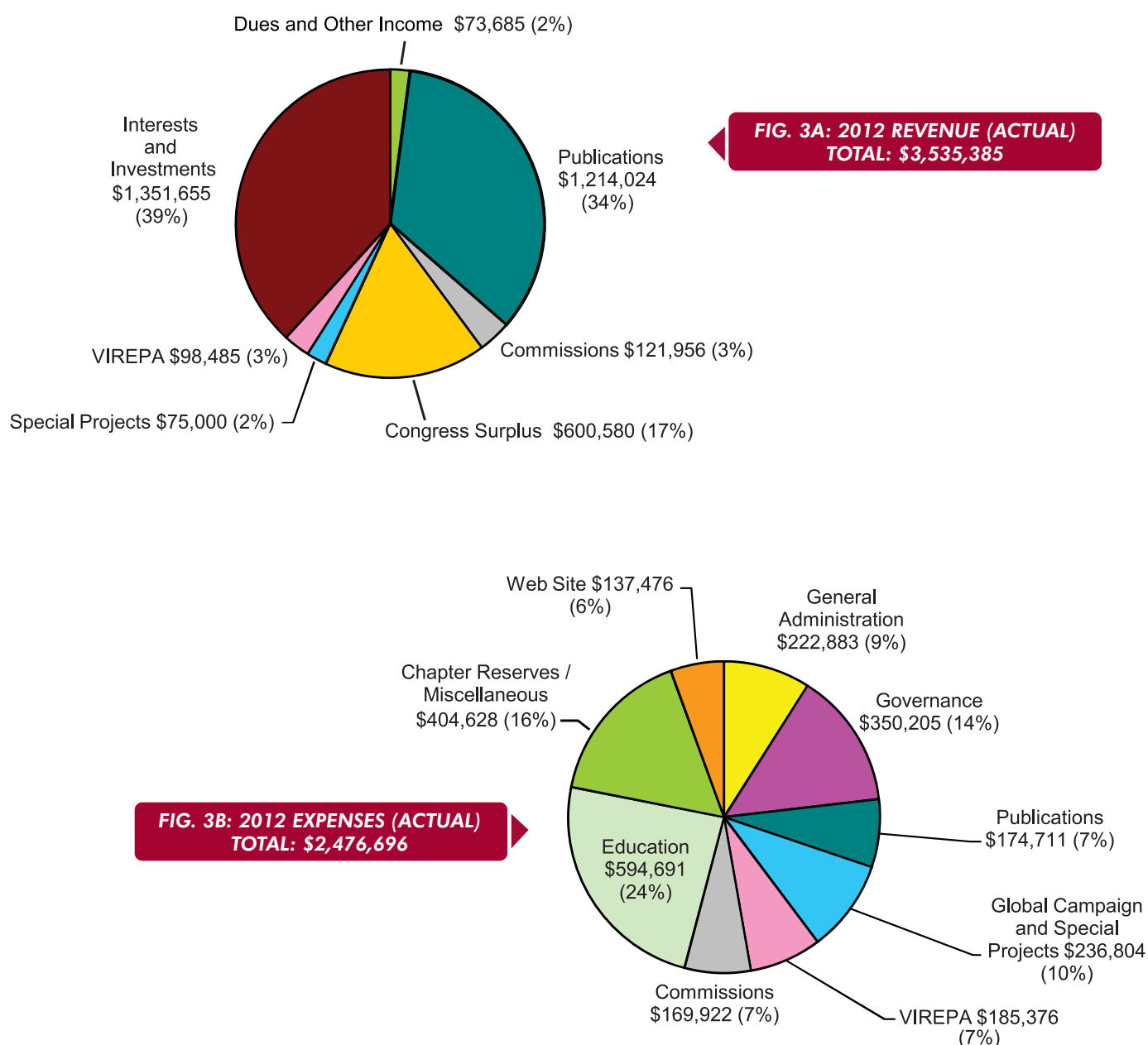


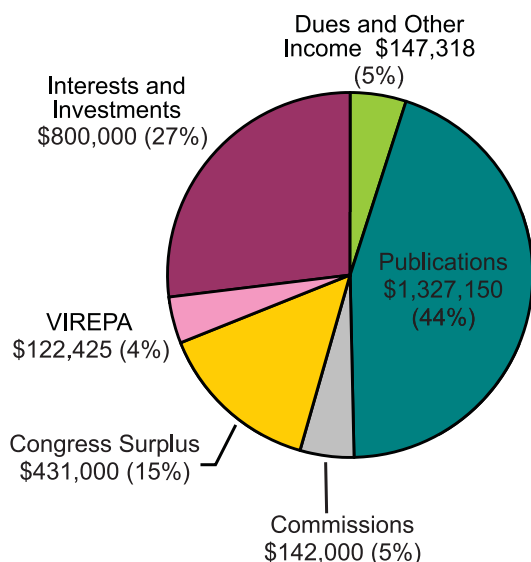
Figure 3 also shows a breakdown of our expenses, with educational activities representing as always the largest area of investment (about one third of the budget, when VIREPA programs are also included). It should be noted that the congresses are a major educational activity; however, for this report we have shown the net surplus as a revenue source. Although at first glance the data in Figure 3 seem to suggest that Commission activities account for only 7% of expenses, it should be considered that a significant part of the activities of Commissions and Task Forces is dedicated to education and special projects, and is therefore listed separately in the figure.



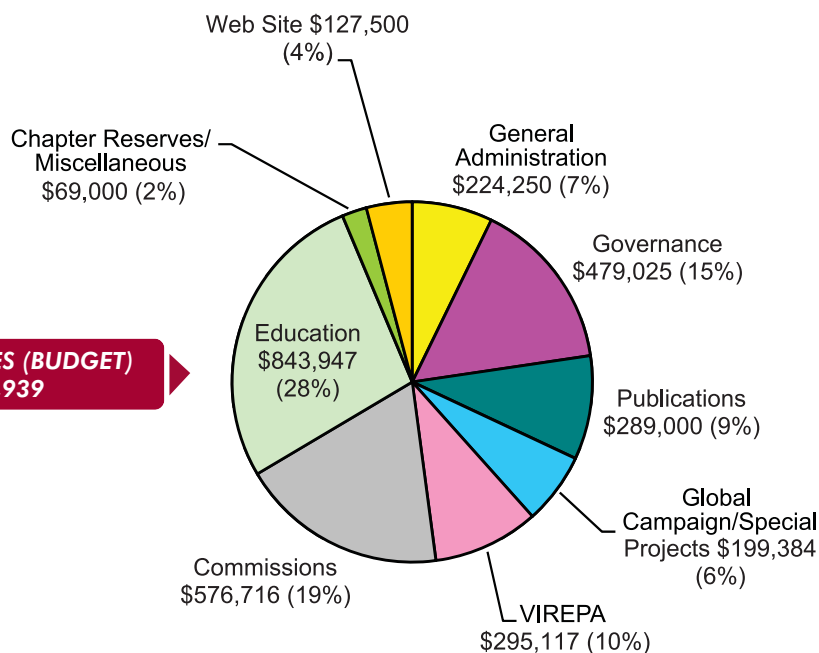
# TREASURER'S REPORT *(continued)*

Projected revenue and expenses in the League's 2013 budget is shown below in Figure 4.

**Figure 4. Projected revenue and expenses in the 2013 budget.**



**FIG. 4A: 2013 REVENUE (BUDGET)  
TOTAL: \$2,969,893**



**FIG. 4B: 2013 EXPENSES (BUDGET)  
TOTAL: \$3,103,939**

As shown in Figure 4, for 2013 we project a 25% increase in expenses over the previous year, with major increases in the budgets allocated for Commissions and for educational activities.

As the 2009 to 2013 term is now closed, I wish to express my thanks for all the support that I have received over the last four years from our President, Dr. Solomon (Nico) Moshé, from all other members of the Executive Committee and from the Chairs and Treasurers of all Commissions and Task Forces. Given my very modest understanding of financial matters, my duties as Treasurer could not have been carried out without the support and guidance from our wonderful Financial Manager, Donna Cunard, and from the members of the Finance Committee, the Advisory Subcommittee, and the Budget Review Committee. I also wish to thank Peter Berry, Priscilla Shisler and Cheryl-Ann Tubby at the AR team, Eve Bolger and Maria McDonnell at the Chancel Office in Dublin, for their support. Last, but not least, I wish to thank the valued and much appreciated assistance from Elena Pigoli and Maddalena Milani at my office in Pavia. For the 2013-2017 term the League will have a new Treasurer, Dr. Sam Wiebe. Having worked closely with Sam, I know that the League's finances could not be in better hands, and I wish him success in his work for the coming four years.

Respectfully submitted,

Emilio Perucca

*ILAE Treasurer (2009-2013)*

# SECRETARY-GENERAL'S REPORT



Samuel Wiebe

It has been a privilege to serve the epilepsy community as Secretary General of the League during the last four years, and to be part of the large number of tasks undertaken by the ILAE Executive during the 2009-2013 tenure. Under the exceptional leadership of President Nico Moshé, The League's family has grown very substantially in numbers, scope and maturity. Salient examples include:

- New ILAE Chapters have been created in almost all continents and additional countries are in the process of assembling chapters. During this tenure, the ILAE General Assembly ratified 24 new Chapters. Most recently Ivory Coast, Rwanda, Democratic Republic of Congo, Bosnia Herzegovina, and the Caribbean Chapter of English Speaking Countries. The ILAE family is now 117 Chapters strong.
- Thanks to Constitutional amendments and to the tireless effort of Dr Amza Ali from Jamaica, for the first time we have a Regional Chapter (The Caribbean Chapter) consisting of a conglomerate of 10 countries: Jamaica, Martinique, St Lucia, Antigua and Barbuda, Trinidad and Tobago, Barbados, St Kitts and Nevis, the Bahamas, Guyana, and soon to join Granada.
- The ILAE Regional African Commission was born and the First African Congress was held in Nairobi.
- All Regional Commissions held at least one Congress. Importantly, the Regional Congresses are becoming a significant forum to address region-specific educational and academic challenges in epilepsy.
- The ILAE Constitution was amended; most importantly, it expanded the Executive Committee to include an elected member from each of its six regions.
- A new slogan was adopted "Stand Up For Epilepsy"
- Important new enterprises were launched in epilepsy, including the areas of Epilepsy in the Tropics, Epilepsy and Sports, Epilepsy Guidelines, and Stigma in Epilepsy around the world.
- The League played a central role in several International developments of momentous importance, including Epilepsy Advocacy Europe, the Pan American Health Organization Strategy for Epilepsy, and the USA Institute of Medicine Report on Epilepsy.
- Finally, new Editors-in-Chief for *Epilepsia* were appointed, and the League acquired the journal *Epileptic Disorders* as its educational journal.

The journey as Secretary-General has been lively and energizing. But above all, I am grateful for the honor of seeing first-hand the enormous needs and gaps in epilepsy care around the world, and the vast effort, dedication and creativity of so many of our members. This is truly a life-changing experience. I salute all of the epilepsy heroes around the world, many of them unsung, who have taught me so much during this term, and for which I am deeply grateful.

A new cycle commences in the leadership of the ILAE, in which I have the distinct honor of serving as Treasurer of the League for the period 2013-2017. I follow in the footsteps of an exemplary Past-Treasurer, and now President-Elect, Dr Emilio Perucca, whose skill and dedication will be difficult to match. Under Dr Perucca's watch the finances of the League stabilized and are well on track to reaching important milestones. Moreover, the level of support to the League's commissions achieved some of the highest levels in the history of the ILAE. The League faces a number of challenges going forward, including a decreasing role of industry in supporting epilepsy worldwide, uncertainty in the world financial markets, and a growing need for support from the League's growing constituencies and initiatives. As incoming Treasurer, I pledge to put forward my best effort in achieving the League's mission with transparent and responsible administration, and to listen attentively to our constituency.

It has been said that "endings, to be useful, must be inconclusive" and this is how I view the transition in the Treasury of the League. I receive from Dr Perucca a legacy of dedication and success that needs to be continued and developed further. I take on the task ahead with a high sense of responsibility, enthusiasm, and anticipation about where our collective Vision will take us.

Samuel Wiebe  
*Secretary-General*

# FIRST VICE PRESIDENT'S REPORT



Tatsuya Tanaka

My activities as the First Vice President and the Chair of the Constitution Task Force during the last four years can be summarized as follows:

## **Achievable Project: Last Four Years of the Term**

The new ILAE Constitution was ratified by the General Assembly at the 29th International Epilepsy Congress held in Rome on August 31, 2011. It ensures that all regions have a voice and a seat in the Executive Committee.

Following ratification of the amended constitution, the League's Bylaws were also amended according to the amended constitution. Thus, the Amended By-Laws were ratified by the Executive Committee on October 2, 2011. The new Bylaws were assured that they were aligned with the approved constitution. Again, this amended Constitution and Bylaws were reconfirmed and ratified at General Assembly during the 30th International Epilepsy Congress held in Montreal in June 2013. I want to express my sincere gratitude to the members of the Constitution Task Force (Drs. Michel Baulac, Marco T Medina, Simon Shorvon and Samuel Wiebe) and members of the Executive Committee (Nico Moshé, Emilio Perucca and Peter Wolf) for their devoted efforts in order to accomplish this hard work during the past four years.

### (1) ILAE election (2013-2017) and the amended Constitution

According to the new Constitution and Bylaws, the President (Dr. Emilio Perucca) and Members of the Management Committee (Drs. Samuel Wiebe, Helen Cross and Tatsuya Tanaka) for the 2013-2017 term were elected successfully according to the process of the new Constitution and Bylaws. Following these elections, Regional Chairs of Six Regional Commissions were also successfully elected (Drs. Amadou Gallo Diop: CAA, Byung-In Lee: CAO, Hassan Hosney: CEMA, Meir Bialer: CEA, Marco Medina: CLAA and Sheryl Haut: CNAA). According to the New Constitution, Regional Chairs are now members of ILAE Executive Committee. The purpose of this important amendment is to better represent its constituency, and the League has amended its constitution to ensure participation of all regions in the governance of the League at the highest level with membership to the Executive Committee. However, the structures and history of each ILAE Regions are very different from each other. For the election of the Regional Chair and members of the Executive Committee, ILAE Constitution and By-Laws should be applied for their election process. Further discussions with the new Election Commission, Constitution Task Force and Executive Committee will be again necessary in order to resolve these important issues for the consistency and transparency of the Regional Election.

### (2) Collaboration with the work of Task Forces and Commissions

As a member of the Conflict of Interest Task Force, an EC Liaison Officer of the Diagnostic Method Commission and an EC Liaison Officer of the Commission of Asian Oceanian Affairs, many collaborative works were performed during the past 12 months. Especially, programming of the 10th Asian Oceanian Epilepsy Congress in Singapore 2014 was already started.

Tatsuya Tanaka  
*First Vice President*  
*Chair of the Constitution Task Force*

# ILAE'S STRATEGIC PLAN, ACCOMPLISHMENTS 2009-2013



Gary Mathern

The ILAE's **vision** is a world in which no person's life is limited by epilepsy

The ILAE'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

Strategic plans are created by organizations to help them fulfill their missions. We break the mission down into several key parts, such as education or patient care, and decide what is most needed in the near term to reach our ultimate goals. These plans are used as a "roadmap" to prioritize the immediate and short-term steps that will take us where we want to go. The ILAE's Strategic Plan was developed after the Budapest Congress, and approved by the Executive Committee (EC) in 2009. As we near the end of this EC's term, it is time to evaluate what was accomplished, and to decide what should be incorporated into the Strategic Plan for the next term.

With the vision and mission statements in mind, Goal 1 of the strategic plan was for the League to be the authoritative resource for current and emerging knowledge on epilepsy diagnosis, treatment, and research. This goal was divided into three aims: develop internationally applicable guidelines for the diagnosis and treatment of epilepsy, enhance international education and training for the prevention, diagnosis, and treatment of epilepsy and to stimulate and enhance basic and clinical research in epilepsy.

Goal 1 is the central identity of the ILAE for many decades (Moshé et al., *Epilepsia* 52:185-197, 2011). The League remains the source for epilepsy classification and in new areas such as classification of cortical dysplasia and hippocampal sclerosis. The League has joined forces with the World Federation of Neurology and the American Academy of Neurology to merge guidelines for the international epilepsy community. The ILAE has also worked in close association with the World Health Organization in incorporating ILAE's 2010 Classification of the Epilepsies into the proposed ICD-11 codes. Education and training is an integral part of our many congresses at the International and Regional Congresses throughout the world. These meetings are supplemented with the online education (VIREPA) and training through a number of regional meetings and courses. The ILAE is supporting the development of the next generation of researchers through sponsored training like the Summer Venice Epilepsy course.

Goal 2 was for the ILAE to serve as an international information resource and leader for optimal, comprehensive epilepsy care. There are four aims under this goal: work with local organizations, Regional Commissions, and partner organizations like the IBE and the WHO through the Global Campaign Against Epilepsy, promote and facilitate initiatives for broad

standards of comprehensive epilepsy care, to interact with governmental groups in establishing the needed resources and to enable all health care professionals to have an active relationship with ILAE.

Again, the ILAE has made substantial progress during the current EC. The Global Campaign Against Epilepsy was re-assessed and became the Global Outreach headed by the Presidents of ILAE and IBE. Over the past four years, the ILAE has participated in regional initiatives about epilepsy care. The League was involved in the 2012 publication of the US Institute of Medicine report on epilepsy, the Pan-American Health Organization plan to improve care throughout the Americas, and the European Initiative with the Written Declaration on Epilepsy. The ILAE continues to work with like-minded organizations such as Vision 20/20 in North America. One of the more exciting initiatives was to link sports figures with persons with epilepsy through the Sports and Epilepsy Task Force (G. Capovilla, Chair) to encourage sports participation by people with epilepsy. The League supports improved communications with continuous evolution of our website to make it more useful and user friendly. The African Commission was a major component of this goal.

Goal 3 was for the ILAE to ensure its ongoing organizational and financial viability, an important issue in uncertain economic times. The four aims of this goal included an examination of our organizational structure for efficiency in fulfilling our mission, enhancing communications and volunteer participation within ILAE, streamlining administrative structure, financial operational practice and, finally, diversifying and enhancing the League's financial resources.

In fulfilling this goal, leadership undertook a comprehensive review of governance, revenue and expenses, and evaluated every aspect of the organization. The Constitution was amended so that regional concerns have a more prominent voice at the EC. Cost saving measures were introduced such as closing the Brussels's office. A Financial Advisory Committee was created with financial experts to assist the League in managing its portfolio and identifying ways to diversify. The League is now in a much stronger organizational and financial position and can focus in the future toward using these resources to fulfill its mission.

Goal 4 was for ILAE to address and implement innovative concepts that advance the League's vision and mission long term. This is an important component of any organization. The ILAE leadership needs to consider the "what ifs" of the future to be ready for these contingencies. These future needs are a regular part of the EC's meetings.

Progress was made on all of the Plan's goals over the past four years, but the task is still incomplete. At the beginning of the new term the goals of the Strategic Plan should be re-assessed and adjusted to assure the success of the ILAE.



# EPILEPSIA REPORT



Gary W. Mathern



Astrid Nehlig

*Epilepsia* had another successful year. Volume 53 (calendar year 2012) comprised 2209 pages, which included twelve regular monthly issues and also the following supplements:

- S1 Neuroanatomical contributions to understanding brain development, plasticity, and neurological disorders: A tribute to H. Jürgen Wenzel – Philip Schwartzkroin, editor
- S2 Classification Revisited – Anne Berg, guest editor
- S3 Electroencephalographic criteria for nonconvulsive status epilepticus: Synopsis and comprehensive survey – Raoul Sutter and Peter W. Kaplan, guest editors
- S4 The Causes of Epilepsy: 10th European Congress on Epileptology, Teaching Course, October 4, 2012, London, UK – Phil Smith, guest editor
- S5 10th European Congress on Epileptology, London, UK, 30 September – 4 October, 2012
- S6 Blood-Brain Barrier and Epilepsy – N. Joan Abbott and Alon Friedman, guest editors
- S7 The Borderland of Epilepsy: Chairs' Symposium, 10th European Congress on Epileptology, London, October 1, 2012 – Phil Smith and Meir Bialer, guest editors
- S8 Phenobarbital: The Centenary, 10th European Congress on Epileptology, London, October 1, 2012 – Meir Bialer and Phil E. M. Smith, guest editors
- S9 Modulation of Epileptogenicity: A Focus on Molecular Plasticity – Philip Schwartzkroin, editor

During 2012, *Epilepsia* received over 1400 submissions and accepted ~ 22% of peer-reviewed manuscripts. The accepted/published manuscripts can be categorized as follows: Reviews (including historical reviews) = 32; Full-Length Original Research reports = 203; Special reports (ILAE Commission reports) = 4; Brief communications = 50; Gray Matter material (not peer-reviewed, including Letters, Commentary, Workshop reports, and various communications) = 26). The editors balance the inclusion of papers likely to be cited with an equally important goal of serving the epilepsy research community by publishing a range of other reports. Financially, the Journal remains highly successful, bringing in net income to ILAE of over US\$1 million.

In terms of circulation and readership, there were 583 institutional subscriptions to *Epilepsia* (a slight decline from 2011), with over 4,000 institutions having licensed access to the Journal. *Epilepsia* also participated in the HINARI program to provide the Journal free of charge to over 3,800 libraries in developing world countries. In 2012 there were over

1,300,000 full-text downloads from *Epilepsia*, reflecting a 39% increase over the previous year. In bibliometric terms, in 2012 *Epilepsia* was ranked 33rd of 193 journals in the Clinical Neurology category, had an Impact Factor of 3.909 and an Eigenfactor of 0.04. The *Epilepsia* Impact Factor was higher than that of any of the other epilepsy sub-specialty journals.

Gary W. Mathern and Astrid Nehlig  
*Editors-in-Chief Epilepsia*

# EPILEPTIC DISORDERS REPORT



Alexis  
Arzimanoglou

Since its launch in late 1999 under the direction of Jean Aicardi, founding Editor-in-Chief, *Epileptic Disorders* has served the medical and scientific community in an expanding discipline of epileptology in which new diagnostic techniques and approaches to management are continually being developed. A significant amount of new information in all areas of epileptology has accumulated at a brisk pace, leading to a steady increase in the number of articles submitted to the journal. As intended from the outset, the descriptive detailed clinical symptomatology and phenomenology of epileptic seizures and syndromes, in relation to diagnosis and management, published in *Epileptic Disorders* has served to complement other journals in the field.

Earlier this year, *Epileptic Disorders* was selected as the official educational journal of the International League Against Epilepsy (ILAE), thus complementing the scope and mission of the ILAE scientific journal, *Epilepsia*. A new educational program is currently being created which will be incorporated into the journal and significantly add to the educational resources already available on the website ([www.epilepticdisorders.com](http://www.epilepticdisorders.com)). The educational program is envisaged to provide unique opportunities for medical students, practicing physicians and basic science trainees who wish to improve their understanding of epilepsy and related pathophysiology, diagnostic challenges, and management.

As the journal takes on this new initiative, the Editorial Board was renewed. Fourteen Associate Editors, covering different epilepsy-related disciplines, will voluntarily contribute their valuable time and professional skills to ensure the quality of the journal and further develop its educational mission, in close collaboration with all Chapters and Commissions of the ILAE.

*Epileptic Disorders* will continue to provide audiovisual material accompanying published articles. Videos are a powerful tool to convey the presentation of clinical events, which by their nature (intermittent, brief, paroxysmal events and abnormal movements) are sometimes difficult to describe in words. Moreover, video sequences co-registered with EEG have now become a fundamental diagnostic tool in our discipline. The inclusion of video material has also proven to be instructive for interpretation of information from neuroimaging, pre-surgical evaluation and neuropathology. The dissemination of video sequences is particularly important for communities, such as those in developing countries, which have a restricted access to educational material. Epilepsy care in such

communities is limited by a lack of resources and in today's age of accessible multimedia, it is highly appropriate to make such resources available through images and web-based communication.

The publisher, John Libbey Eurotext editions, will pursue the development of the website, with emphasis on educational resources and easy access to a library of video data. The proceedings of a number of topic-oriented workshops, published in the book series *Progress in Epileptic Disorders*, are also accessible via the website.

The new educational focus underlines the mission of ILAE and the journal to improve epilepsy knowledge worldwide, with the ultimate goal of better care for people with epilepsy.

Alexis Arzimanoglou  
*Editor-in-Chief*

# INFORMATION OFFICER REPORT



Edward Bertram

The Information Officer has several defined duties and provides support for several organizational goals. The defined duties are developing and editing each edition of Epigraph and creating League announcements and communications on behalf of the President and the Executive Committee. Another duty, less well defined, is promoting the goals of the ILAE to the epilepsy community and to governments and health care agencies. The League goals include fostering a sense of community within the international epilepsy family, increasing the awareness of the extraordinary work that is being done by our colleagues under at times very difficult conditions, raising the visibility of epilepsy as a serious disease and encouraging greater support for epilepsy treatment and research across the globe. The last several years have been gratifying for all areas.

Epigraph is the League's newspaper. It contains the thoughts and plans from the leadership, announcements of upcoming events, and articles about the activities of our colleagues from all of our regions about what they are doing to support the League's mission to improve the condition of people who suffer from epilepsy. In the last several years the articles have been as diverse as our membership. Gallo Diop wrote about outreach programs in rural Senegal, and Lionel Carmant updated us on the programs to make epilepsy care more accessible in Haiti. Helen Cross, Shichuo Li and Hanneke de Boer described the success of the Global Campaign (now Global Outreach) in closing the treatment gaps in many countries, including China and Brazil. Karijn Aussems reported the value of patient based programs such as Youth on the Move in Kenya in reducing the stigma that is associated with epilepsy, and Dave Clarke, Amza Ali, Tamika Haynes-Robinson and Aubrey Webson gave us some insight into the considerable efforts that were involved in creating a multinational League chapter such as the Caribbean Chapter that will allow countries with a common heritage to overcome the limitations that a small population may place on epilepsy resources. In discussions with our many colleagues around the world it is clear that there are far more stories to report every year. In the coming year we look to bring more news about the extraordinary efforts by members of the epilepsy community to alleviate the burdens the epilepsy causes.

Epilepsy has suffered from a lack of resources because health care systems have generally not viewed the disease as a major burden in relation to other diseases, even though the data consistently show that epilepsy represents a significant portion of the global burden of disease and is associated with a higher annual mortality than breast cancer. Part of the problem is that epilepsy is in many respects an invisible disease, as

many hide their affliction. The "Out of the Shadows" campaign worked hard to reduce the stigma of epilepsy so that people would no longer feel the need to deny the disease. The League and its chapters and regions have worked hard to make governments and health care agencies aware of the need to allocate greater resources to epilepsy. Successes have been achieved through the agreement with the Pan American Health Organization, the Institute of Medicine report on Epilepsy and the European Declaration. Each was released with much publicity and excitement. However, the concern has been that after the initial flurry of activity, the momentum would slow, and the effort would be displaced as other issues assume a higher priority and push epilepsy once again to the side. To counteract this problem, the League took the initiative to keep the issue of epilepsy visible to government health agencies by contacting them directly, typically to thank them for their support for multinational agreements, but often to inform them of significant contributions that our epilepsy colleagues have made while at the same time reminding them of the major health care problems and costs that are the result of epilepsy. We have been gratified by the comments that we have received from our colleagues about how helpful these letters have been in making the seriousness of epilepsy more visible and in catching the attention of government agencies. We will continue to work with this effort to call attention to the underfunding of epilepsy to those who allocate health care resources whenever the opportunity arises.

As we look towards how to continue the task of making epilepsy more visible and enhancing communication within the family, there are a number of challenges, not the least of which is language. Much of the truly creative work is being done where English is not in widespread use and the comfort level for writing in English is not high. In addition, while in the middle of a project, it is not always obvious to the participants that what they are doing may have usefulness for others. Because the stories are important, we will first work to identify the topics and then assist with the writing. Everyone working in epilepsy has important experiences to share, and the experiences will teach the rest of us new ways to make the lives of people with epilepsy better. It has been a privilege as Information Officer to learn from so many and to help make their stories known.

Edward Bertram  
*Information Officer*

# INTERACTIVE MEDIA REPORT



Jean Gotman

## Highlights

We continued with our goal of making the ILAE website ([www.ILAE.org](http://www.ILAE.org)) more informative and rapidly responsive in the context of the ILAE mission. The number of visits to the ILAE website has increased continuously in the last five years from 116,000 in 2009 to 197,000 in 2013 (Figure 1). Between 2012 and 2013 the increase was 37%. In addition, the “bounce rate” (proportion of visits where the visitor sees only the page on which they landed, reflecting probably a limited interest in the website) has decreased from 50 to 31%. Graphs and details about web activity are shown in Appendix 1.

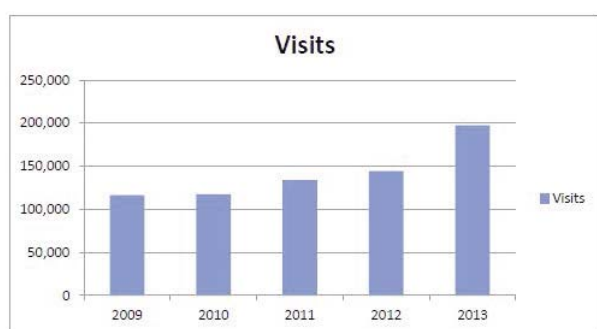


Figure 1

In the spring of 2013, we conducted brief surveys of visitors to the website. Even though these are not scientific, they provide valuable information. The major results are given in Appendix 2. We were struck by a few points:

- A significant proportion of visitors are not medical professionals; among people with medical background there is an important group of students/interns/residents
- A large fraction of visitors, medical professionals or patients/caregivers, are seeking information about epilepsy (as opposed to information about ILAE such as congresses)
- The majority of visitors are not members of ILAE chapters

This indicates that through the website, ILAE reaches a constituency well beyond its formal members (chapter members). This constituency is medical and lay and seeks information about epilepsy. We feel that the ILAE generates from its activities much reference information about epilepsy and is therefore uniquely positioned to make this information known to a broad public.

## Operations

Our Web Manager Deb Flower started at the beginning of 2013 and this position has proven a major asset in having a very responsive, up-to-date and accurate site. Programmer Steve Shane has provided support for the structural changes to the site. The daily supervision of activity is provided by Priscilla Shisler. The web team meets for a weekly conference call.

## Changes to the Website

### HOME PAGE FEATURES

Using the design features implemented in 2012, we refreshed content in the center and right panels of the home page frequently, and added a scrolling news bar at the top of the page. In addition to posting links to journal articles of interest, farewell tributes, chapter changes, and other regular items, we used these two main panels to highlight the following features, with a major change every few weeks: awards, elections, SUFE, guidelines, IEC registration and follow up, *Epileptic Disorders* and *Epilepsia*, upcoming congresses.

### REACH OUT/CREATE COMMUNITY

Used the website to engage and inform our members:

#### E-Newsletter

Adopted a plan for *brief* monthly e-newsletters to inform members of ILAE activities, with links to supporting material on the site.

#### Request for comments for League official position papers

Implemented the new process of gathering public comments on League official position papers. The request for comments for the first paper, Definition of Epilepsy, proved very successful, with more than 300 responses. The same was done with the Classification of the Epilepsies document.

#### Elections

Posted progress during all phases; featured results for all elections. Also ensured that member rosters for commissions, committees and task forces are up to date. Election results remain archived on ILAE site and commission sites as appropriate

### EXECUTE MISSION

We believe the website should advance the ILAE's mission 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.”

#### Epilepsia

We have established a closer working relationship with *Epilepsia* and now promote it more strongly in a regular space on the home page. We continue to post Editor's Choice and Gray Matters, in addition to featuring articles of special interest in our “News” section.

#### Epileptic Disorders

Created a section on the website to feature our new journal, *Epileptic Disorders*.



# INTERACTIVE MEDIA REPORT *(continued)*

## **Patient and care providers**

Consolidated information to create a resource page for persons with epilepsy and caregivers

## **CONTINUAL IMPROVEMENTS**

Behind the scenes, we undertook changes to improve functionality and freshen content. Examples:

### **Awards**

Modified the Awards pages for a cleaner, more logical presentation

### **Chapters**

- Integrated chapter data into the membership database to facilitate appropriate interface and functionality with website and commission sites, while allowing better use of membership database capabilities for electronic communication with chapters and regions. This was a major undertaking.
- Added world map to the Chapter landing page illustrating the location of chapters

### **Congresses**

Enhanced the International and Regional Congress archive pages to include links to programs, abstracts, photos, and testimonials, where available

### **Bookstore**

Improved the Bookstore search and display functionality (now called Books on Epilepsy)

### **Guidelines**

Reorganized and consolidated the Guidelines and Reports pages

## **Social Media**

We continue with our presence in social media, where our activity is receiving greater attention. We currently have 503 “likes” on Facebook and 378 followers on Twitter (up from 126 and 134, respectively, at the end of 2012).

## **Budget**

The 2014 web budget is decreased by more than 25% over the 2013 budget. This is in part due to the completion of the chapter data integration project under Continual Improvements. Cost savings will also be achieved with a modification to the Commission websites which will allow them to remain accessible from the League website without the use of a third-party vendor.

## **Plans for 2014**

We plan to continue our various activities to provide useful information about ILAE and reach a broad community through the web site, social media and e-newsletters. The Communication Task Force started operating at the end of 2013 and we will work in close collaboration with this Task Force, looking for guidance in the development of activities in the area of Interactive Media. We are planning to improve communication with the Congress organization (IDM) to ensure a smooth flow of information between the two and a uniformity of messages to the outside world. We will continue our efforts to work closely with the publications of ILAE (*Epilepsia*, *Epileptic Disorders*, *Epigraph*).

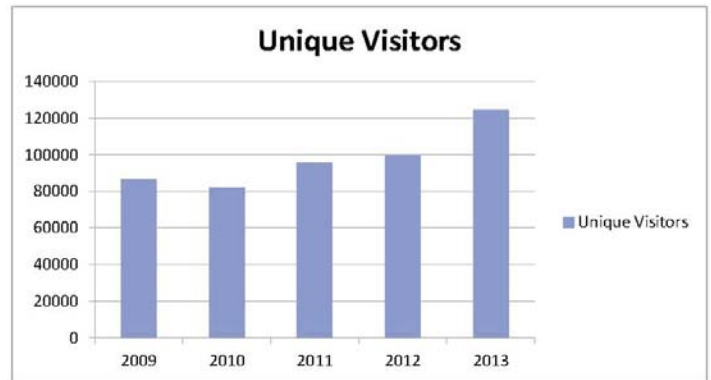
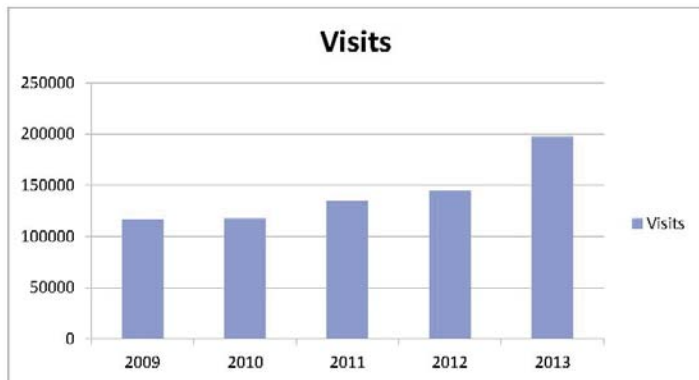
Jean Gotman, *Director of Interactive Media*

# INTERACTIVE MEDIA REPORT *(continued)*

## Appendix 1: Web Statistics

### 2013 Year End Analytics 5 Year Overview

	Site Overview: 5 Years				
	2009	2010	2011	2012	2013
Visits	116,382	117,578	133,958	144,360	197,597
Unique Visitors	86,505	82,084	95,662	100,135	124,535
Page Views	399,239	406,796	391,217	426,175	689,009
Unique Page Views	289,973	297,427	291,702	283,901	381,438
Pages/Visit	3.43	3.46	2.92	2.95	3.49
Avg Visit Duration	0:02:43	0:03:00	0:02:41	0:02:41	0:02:47
Avg time on page	0:01:07	0:01:13	0:01:22	0:01:21	0:01:06
Bounce Rate	49.58%	49.09%	56.64%	46.54%	31.30%
index/home page views	54,468	67,871	75,213	83,212	95,281



**Visits** represent the number of individual sessions initiated by all the visitors to the site. If a user is inactive on the site for 30 minutes or more, any future activity will be attributed to a new session. Users that leave the site and return within 30 minutes are counted as part of the original session.

**Unique Visitor:** Unique visitors refers to the number of individuals requesting pages from the website during the reporting period, regardless of how often they visit. When an individual goes to a website on Tuesday, then again on Wednesday, this is recorded as two visits from one visitor.

**Pageview:** view of a page on the site. A new view for a particular page is counted each time a visitor lands on a page or returns to the page after navigating to a different page.

**Unique page view:** Aggregation of all views of a single page by a single user during a single session. In other words, each page that a user views within one session is counted once, no matter how many times they return to that page.

**Bounce Rate:** The percentage of visitors who enter the site and "bounce" (leave the site) rather than continue viewing other pages within the same site. Visitors who "bounce" only look at the page on which they entered the site.

## Detailed Report

# INTERACTIVE MEDIA REPORT (continued)

Most Viewed Pages			Page Views		Unique Views		Most Viewed Documents		Views		Unique Views	
Page Name	2012	2013	2012	2013	2012	2013	Document Name	2012	2013	2012	2013	
Home Page	83,133	95,281	64,582	68,260			Organization of the Epilepsies - 2010		7,263		6,730	
Classification & Terminology index	41,519	66,472	22,879	32,715			New classification proposal (brief ver 2011)		6,136		5,660	
Congresses	18,708	40,335	12,533	25,419			Definition Of Epilepsy		5,868		5,402	
Guidelines	15,993	33,849	10,756	18,787			Org. of the Epilepsies 2010-Quick Overview		4,197		3,829	
Definition of Epilepsy	n/a	30,010	n/a	13,785			ILAE evidence review of AED efficacy 2013		3,165		2,893	
VIREPA	14,302	20,496	6,705	9,050			ILAE Org. of the Epilepsies – short talk		3,049		2,755	
Epilepsia	10,778	20,293	4,984	8,056			Org. of the Epilepsies 2010 - Spanish	N/A	2,413	N/A	2,193	
Chapter landing page & Select Chapter	13,247	12,261	6,720	5,798			ILAE Treatment Guidelines		1,929		1,776	
ILAE Courses	6,968	12,089	4,034	5,636			ILAE Treatment Guidelines PPT Presentation		1,290		1,200	
Epileptic Disorders	n/a	5,054	n/a	2,047			Quick Overview of the 2010 prop-Spanish		1,267		1,157	
Epilepsia Editor's Choice	1,596	4,140	897	1,904			VIREPA - EEG Basic Course Details		1,202		1,081	
Organization of the Epilepsies	n/a	3,706	n/a	1,669			Treatment Guidelines Excel spreadsheet		895		837	
Classification & Terminology glossary	1,445	3,591	1,212	2,989			VIREPA - EEG Score Course Details		858		787	
Epilepsy Brochures & Translations	3,621	3,073	2,055	1,351			Org. of the Epilepsies 2010 - Portuguese		768		709	
About ILAE	2,708	2,714	2,153	2,200			Sleep & Epilepsy Course Details		758		687	
Total page views for ALL pages			425,790	689,009	283,586	381,438						
											</	

Note: Document tracking was phased-in beginning 6/1/12

Visits by Location (as % of total visits)		2012	2013
United States	19.37%	27,919	35,193
United Kingdom	9.46%	13,645	16,438
India	4.06%	5,856	9,838
Canada	3.74%	5,393	8,426
Mexico	3.07%	4,426	6,884
Brazil	2.55%	3,679	6,744
Germany	3.31%	4,773	6,473
Italy	3.38%	4,872	6,278
Japan	2.50%	3,603	5,250
Australia	2.50%	3,608	4,798

Visits by Location		2012	2013	% Change
United States		27,919	35,193	26.05%
United Kingdom		13,645	16,438	20.47%
India		5,856	9,838	68.00%
Canada		5,393	8,426	56.24%
Mexico		4,426	6,884	55.54%
Brazil		3,679	6,744	83.31%
Germany		4,773	6,473	35.62%
Italy		4,872	6,278	28.86%
Japan		3,603	5,250	45.71%
Australia		3,608	4,798	32.98%

**Pageview:** view of a page on the site. A new view for a particular page is counted each time a visitor lands on a page or returns to the page after navigating to a different page.

**Unique page view:** Aggregation of all views of a single page by a single user during a single session. In other words, each page that a user views within one session is counted once, no matter how many times they return to that page.

**Visits** represent the number of individual sessions initiated by all the visitors to the site. If a user is inactive on the site for 30 minutes or more, any future activity will be attributed to a new session. Users that leave the site and return within 30 minutes are counted as part of the original session.

# INTERACTIVE MEDIA REPORT (continued)

## Appendix 2: Web Surveys

**Survey 1: 2/5/13 – 2/19/13** 617 respondents

**Which of these choices best describes you? [Select all that apply]**

Respondents were permitted to select more than one answer

Resident/Fellow/intern/student	106	15%
Research or academic/Ph.D.	95	14%
Adult Neurologist	81	12%
Epileptologist	73	10%
Pediatric Neurologist	70	10%
Other	62	9%
Practicing physician/MD	51	7%
Caregiver	48	7%
Person with epilepsy	47	7%
Nurse or physician's assistant	39	6%
Neurosurgeon	12	2%
Medical technician	12	2%
Total	696	100%

**Survey 2: 3/11/13 – 3/25/13** (15 d): 458 respondents

(There were more answers, because they were allowed to select more than one category.)

**Why did you come to the ILAE website? [Select all that apply]**

General information about epilepsy for Medical Professional	182	24%
Guidelines about Anti-Epilepsy Drugs and other guidelines	136	18%
Classification reports for organization of the epilepsies	130	17%
Epilepsy Congress/Meeting information	90	12%
General information about epilepsy for Caregiver/patient	86	11%
Epilepsia Journal	68	9%
Virtual Epilepsy Academy (VIREPA) course information	36	5%
Other [See page 3]	32	4%
	760	100%

**Survey 3: 4/10/13 – 4/29/13** (20d) : 632 respondents

**Are you a member of an ILAE chapter?**

No	436	69%
Yes	123	19%
No response	48	8%
Not sure	26	4%
	633	100%

**Did you come to this site to find information about:**

Epilepsy	417	66%
ILAE	136	21%
No response	51	8%
Other (please specify)	29	5%
	633	100%



# GLOBAL CAMPAIGN REPORT



Helen Cross



Hanneke de Boer



Shichuo Li

The WHO, ILAE and IBE joined forces in 1997 in partnership as the ILAE/IBE/WHO Global Campaign Against Epilepsy (GCAE) – “Out of the Shadows,” with its mission statement: To improve the acceptability, treatment, services and prevention of epilepsy worldwide.

Acknowledging that there are many activities that may embody the ethos of the Campaign, in 2009, a Task Force was formed with an aim to establishing a strategic plan with action points to forward wider development of activities within the GCAE, and raise awareness of achievements. The final strategic plan had four main goals:

1. To improve the visibility of epilepsy and the activities of the Global Campaign in all countries
2. To promote activities of all epilepsy projects on a country and regional level
3. To assess and strengthen health care systems for epilepsy
4. To increase partnerships and collaboration with other organizations

It became clear however that throughout the world there were many initiatives that could be interpreted as of global relevance, but such activities were not necessarily directed through the collaborative efforts of the GCAE. The Task Force was therefore renamed that for “Global Outreach” with a primary aim of raising awareness of global educational and service initiatives in epilepsy throughout the world.

Examples of activities that have been undertaken within the remit of the Task Force for Global Outreach over the last four years have included:

1. Launching of the Global Campaign website in June 2010 at the European Congress in Rhodes, [www.globalcampaignagainstepilepsy.org](http://www.globalcampaignagainstepilepsy.org), with information about current activities, regional reports and updated information about demonstration projects;
2. Development of a new slogan “Stand Up For Epilepsy” for use worldwide;
3. Completion of a Demonstration Project in Georgia in 2011. Demonstration projects remain a key activity of the Global Campaign Against Epilepsy with an objective of reducing the treatment gap and social and physical burden, educate health personnel, and dispel stigma with an ultimate goal of developing a variety of successful models of epilepsy control that can be integrated into the health care systems of the participating countries and regions and, finally, applied on a global level. The possibility of further projects is being explored in Ghana, Vietnam, Cameroon and India, and a project is currently underway in Honduras;
4. Completion of a model for assessment of epilepsy services and resources, piloted in Tajikistan, with plans for replication in two further European countries;
5. Regional reports on epilepsy published in EMRO and EURO and launched at stakeholders meetings in the respective regions. Such reports have now been published in all regions of the world, and stakeholder meetings were held in all six regions during this term. In particular, specific initiatives have been undertaken:
  - a. A strategic plan for epilepsy from the program for Mental Health and Neurological Disorders was developed for implementation in Latin America within PAHO. On November 14, 2012, the Pan American Health Organization (PAHO/WHO), the International League Against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE) signed a Memorandum of Understanding that bonds them in a 10-year-long partnership to deploy the Strategy and Plan of Action on Epilepsy for the American continent.
  - b. The Institute of Medicine Report on Epilepsy in the USA
  - c. A written declaration on epilepsy passed through European Parliament in 2012. A European Research Forum took place May 2013.
6. A CD containing a number of publications under the auspices of the Global Campaign was produced.
7. Completion of the documents that had been developed within the project on Epilepsy and Legislation “*Basic Principles for Epilepsy Legislation*” (setting out basic principles and rights that should be considered when drafting legislation related to epilepsy) and the “*Guidance Instrument for developing, adopting and implementing epilepsy legislation*” produced on CD, disseminated during the International Epilepsy Congress in Montreal, Canada.
8. A CD containing the history of the Campaign was completed and was available during the congress in Montreal.
9. The Global Campaign had a stand on the joint ILAE and IBE International Congresses on Epilepsy, where progress of its activities were promoted on posters and leaflets as well as a small poster exhibition of its history, which was shown in Montreal.
10. Jointly published WHO guidelines on management of neonatal seizures, and within the WHO mental health Gap Action Programme (mhGAP)

# GLOBAL CAMPAIGN REPORT *(continued)*

contributed to the development of the chapter on epilepsy in the evidence based intervention guide for the management of mental, neurological and substance use disorders in non-specialized health settings.

11. Contribution to the new WHO Global Burden of Disease project that will result in comprehensive estimates of the burden of epilepsy, its disabling sequelae and its role as a risk factor for other diseases and injuries.

Activities continue on a global scale, and it remains within the remit of the Task Force to raise awareness of such initiatives, encouraging dissemination of information on activity.

Helen Cross  
Shichuo Li  
*Co-Chairs Global Campaign*

Hanneke de Boer  
*Secretariat GCAE*

# STAFF REPORT



Priscilla Shisler

The past year has been a busy one, and a year of transition for the League as accomplishments from the last four years are celebrated and a new term begins. The ILAE Headquarters and Chapter Services staff is energized by the dedication, expertise and passion of the many individuals involved in the important initiatives and activities of the League. We are committed to providing a high level of project and resource management in support of those initiatives and activities. Below are some of the efforts in which we have been involved during the last year.

- Collaborated with the Elections Committee for the elections of the Executive and Regional Commissions for the 2013-2017 term
- Provided assistance to the outgoing and incoming Commission and Task Force Chairs with the transition to the 2013-2017 term
- In partnership with the Executive Committee, coordinated the Chapter Application process for Bosnia and Herzegovina, Democratic Republic of the Congo, Ivory Coast, Rwanda and the Caribbean Chapter, all of whom became full members of the League at the General Assembly in Montreal
- Provided administrative support during the League's recent acquisition of *Epileptic Disorders*, the League's new educational journal
- Upgraded the membership database to enhance the capabilities for efficient and timely communication with Chapters and Regions. Increased the number of Chapter members in the membership database through liaison with all Chapters
- Improved the VIREPA Distance Education Program with the introduction of a new eLearning platform powered by the open source software, Moodle, including the development of user manuals
- Assisted in coordinating the move of the League's archival materials to the Wellcome Trust in the UK for cataloging and curation
- Worked closely with the Executive Committee to plan and prepare for the Chapter Convention and General Assembly at the IEC in Montreal which saw nearly 2/3 of the 115 Chapters in attendance and the official inauguration of the new Executive Committee for the 2013-2017 term
- Expanded the Chapter Poster Display initiative at the IEC in Montreal providing an opportunity for each Chapter to promote the work that they are doing to a global audience
- Designed and staffed the ILAE booth in Montreal which provided a meeting point for Chapters and an opportunity to meet with the staff, pay dues, learn about Congresses and VIREPA courses, and about

other Chapters and what's happening in the regions. Note that if there are any suggestions about how the booth experience can be improved let us know by contacting Gus Egan [gegan@ilae.org](mailto:gegan@ilae.org)

- Worked in close collaboration with Jean Gotman, Director of Interactive Media, to execute the League's mission and create community by continually improving the League's website
- Assisted and advised the Treasurer, the Budget Task Force and the Commission Chairs in the development of the annual budget
- Coordinated with and assisted the Finance Committee and Finance Advisory Committee to ensure compliance with the League's Investment and Cash Management Policies

I am proud to work beside the Headquarters and Chapter Services staff and want to thank them for being the bright, creative and hard-working group of individuals they are – Donna Cunard, Gus Egan, Simone Upsey, Verena Hézser-v.Wehrs, Mary Anne Lynch, Deborah Flower and Steve Shane.

The newest members of our staff are Simone Upsey and Mary Anne Lynch.

Simone Upsey serves as the League's Communications Liaison. She works on communications projects such as *Epigraph* and the Annual Report, interfaces with the Website Team, and Communications and Publications Task Forces as needed. In addition, she assists in supporting the Executive Committee, Commissions and Task Forces.



Mary Anne Lynch joined the Headquarters staff to support the growing Virtual Epilepsy Academy (VIREPA). She coordinates three VIREPA courses alongside Priscilla and Verena Hézser-v.Wehrs, the lead ILAE VIREPA Coordinator, and has assisted with the implementation of the new eLearning platform.



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



Gus Egan is based in the Chapter Services Office in Dublin, Ireland. Gus 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 and promotes the League through the use of the booth.



# STAFF REPORT *(continued)*

Verena Hézser-v.Wehrs is the Lead Coordinator for the VIREPA distance education program. Working closely with the Education Commission, Course Directors and Tutors, she administers, moderates and evaluates the VIREPA program. Verena also collaborates in the development of new courses and formats.



Deborah Flower supports the League in the position of Web Content Administrator and is responsible for web content management, designing, executing, and testing web content and functional enhancements. She also assists with the eNewsletter and *Epigraph*.



Steve Shane provides technical support for the website and the VIREPA distance learning program and is responsible for developing new web applications and software solutions, while maintaining and enhancing existing applications.



Priscilla Shisler, MEd  
*Administrative Director*



# INTERNATIONAL DIRECTOR OF MEETINGS REPORT



Richard Holmes

## 2012

From January to December 2012, the Congress Team managed four congresses, including the 9th AOEC and the 1st AEC in the first half of the year, with 5,807 attendees and 676 speakers and chairs; 1,169 abstracts were received and 209 bursaries were awarded.

### 10th European Congress on Epileptology, London, United Kingdom 30 September-4 October 2012



**Organizing Committee:**  
IOC Chairs: Meir Bialer (Israel), Philip Smith (United Kingdom)

**SAC Chair:** Simon Shorvon (United Kingdom)

**Venue:** ICC London ExCeL

**Awards presented:** European Epileptology Award; British Branch Excellence in Epilepsy Award; Morris-Coole Epilepsia Prize; CEA Awards for Service, Education and Young Investigator

#### Congress program:

- Four main themes: basic science of epilepsy; imaging and surgery; clinical epileptology and neuropsychiatry; clinical pharmacology and drug therapy.
- The Nobel Lecture series – daily talks given by a Nobel Laureate or Field Medallist.
- Epilepsy Olympiad – an epilepsy tournament for national Chapters, won by Ireland.
- A coordinated teaching course on the “Causes of epilepsy,” hosted by the ILAE UK Chapter, was held on the last day of the congress.
- Strong focus on posters, including Poster Tours led by key experts and Best Poster Presentations in the poster area daily.

#### Other highlights:

- The photographic exhibition, “Stand Up For Epilepsy,” was launched by the ILAE Taskforce on Sports and Epilepsy.
- A historical exhibition, “The beginning of the end of the falling sickness: Epilepsy and its treatment in London 1860-1910.”

### 7th Latin American Congress on Epilepsy, Quito, Ecuador 14-17 November 2012



#### Organizing Committee:

Chairs: Lilia Núñez Orozco (Mexico), Marco Tulio Medina (Honduras), Patricio Abad (Ecuador)

**Venue:** Hilton Colon Quito Hotel

**Awards presented:** ILAE-CLAA awards for outstanding achievement in epilepsy; ILAE-CLAA Lifetime Achievement Award; ILAE Latin American Ambassadors; ILAE Chapter Recognitions; Sociedad Ecuatoriana de Neurología / Liga Ecuatoriana Contra la Epilepsia Awards

#### Congress programme:

- Presidential Plenary Session (ILAE/IBE/PAHO/WHO): “Epilepsy for the Americas.”
- Educational courses organized by the Latin American Epilepsy Academy (ALADE): Neurobiology; Pharmacology; Genetics of epilepsy; EEG and Semiology of seizures.

#### Other highlights:

- Activities introducing and implementing the PAHO “Strategy and Plan of Action on Epilepsy” (Estrategia y plan de acción sobre epilepsia), which aims to prioritize epilepsy in health care throughout the Americas.
- Concert at the Casa De La Música.

## 2013

During 2013, the Congress Team managed three congresses with 2,910 attendees and 361 speakers and chairs; 1,177 abstracts/posters were received and 90 bursaries were awarded.

### European Forum on Epilepsy Research, Dublin, Ireland 25-27 May 2013



#### Organizing Committee:

Chairs: Mike Glynn (Ireland), Emilio Perucca (Italy)

**Venue:** The Convention Centre Dublin

#### Background:

- The EFER, an activity of Epilepsy Advocacy Europe, an ILAE/IBE Joint Task Force, was a ground-breaking collaborative research conference, partly funded by the 7th Framework Programme of the European Commission in conjunction with the Irish Presidency of the European Union.

# INTERNATIONAL DIRECTOR OF MEETINGS REPORT *(continued)*

- The Forum targeted an optimum mix of delegates including researchers, clinicians, neurologists, primary care professionals, medical and postgraduate students, industry, persons with epilepsy, health policy makers, European and national government representatives and European Parliament and Commission officials.

## Conference program:

- The proposition of the Forum was to take a strategic view and identify research priorities ahead of the opportunities of Horizon 2020.
- Program Topics: "Burden and Stigma of Epilepsy"; "Standards of Care"; "Epilepsy in the Developing Brain"; "New Targets for Innovative Diagnostics and Treatment"; "What is Required for Prevention and Cure?"; "Think Big – Aiming for the Horizon 'No Seizures, No Epilepsy'"; "Epilepsy and Co-Morbidities – Special Focus on Aging and Mental Health."
- Additional sessions: "Workshop: How to Increase Support for Epilepsy Research and Access Funding Opportunities"; "Influencing the Political Agenda."

## 30th International Epilepsy Congress, Montreal, Canada 23-27 June 2013



### Organizing Committee:

Chairs: Mike Glynn (Ireland), Solomon L Moshé (USA)

**Venue:** Palais des congrès de Montréal

**Awards presented:** Ambassador for Epilepsy Awards; Michael Prize; Morris-Cooles *Epilepsia* Prize; Social Accomplishment Award; Lifetime Achievement Award

### Congress program:

- Main topics: "Challenges for epilepsy surgery in the developed and developing world"; "Stigma in epilepsy – who, why and what to do?"; "The epileptic focus: a zone or a network?"; "Withdrawing AEDs – the brain, the patient and the family"; "The new organization of the epilepsies in daily practice"; "Focal cortical dysplasia – the latest"; Presidential Symposium: "Epilepsy: beyond seizures."
- Special symposia: "Epilepsy at the Montreal Neurological Institute – The pioneers: early concepts in today's practice"; IBE Symposium "Making the case for IBE's International Advocacy"; Neurobiology Symposium "Role of non-neuronal cells in epileptogenesis."
- New additions: Meet the Experts sessions; Controversies sessions; Epi-Quiz.
- A comprehensive teaching program, with courses each morning.

## Other highlights:

- Reduced registration fees for Allied Health Professionals (AHP) or Non-Medical Health Professionals. Additional discount of 50 EUR for IBE and ILAE members. Reduced registration fee also for delegates coming from lower income countries.
- A strong emphasis on posters, with Poster Tours led by experts each day.

## 13th European Conference on Epilepsy & Society, Ljubljana, Slovenia 28-30 August 2013



### Organizing Committee:

Chair: Athanasios Covanis (Greece)

**Venue:** Cankarjev Dom Cultural and Congress Centre (CD)

### Conference program:

- The theme of the conference was "Break Down the Barriers and Stand Up for Epilepsy."
- On this occasion and for the first time, the ILAE-CEA made a financial contribution to the ECES, for a workshop entitled "Advocates for Epilepsy," which took place on the day prior to the main conference program. The workshop focused on topics to develop strategies to help the audience better understand and support the individual living with epilepsy, using a person-centered approach.
- All delegates under 35 years of age and delegates from Albania, Estonia, Georgia, Macedonia, Serbia, Russia, Moldova, Ukraine and Bulgaria were entitled to free registration.

## 2014

## 2nd African Epilepsy Congress, Cape Town, South Africa 22-24 May 2014



### Organizing Committee:

Chairs: Amadou Gallo Diop (Senegal), Anthony Mulenga (Zambia)

**Venue:** The Westin Cape Town

### Congress program:

- Chairs' Symposium: "Bridging the Gap in Africa."
- Plenary Session: "Diagnosis of epilepsy."
- Session topics include: "Causes of epilepsy"; "Treatment options"; "Childhood epilepsy"; "Management of epilepsy."
- Round Table Discussions: "Epilepsy surgery in resource-poor settings"; "The role of EEG";

# INTERNATIONAL DIRECTOR OF MEETINGS REPORT *(continued)*

"Educational programmes in epilepsy"; "Epilepsy management guidelines and their implementation."

## 11th European Congress on Epileptology, Stockholm, Sweden 29 June-3 July 2014



**Organizing Committee:**  
IOC Chairs: Meir Bialer (Israel), Kristina Malmgren (Sweden)

SAC Chair: Torbjörn Tomson (Sweden)

**Venue:** Stockholmsmässan

**Awards to be presented:** European Epileptology Award; European Epilepsy Education Award; Young Investigator Awards; European Epilepsy Service Awards

### Congress program:

- Four main themes: basic science; epilepsy surgery; pharmacotherapy; pediatric epileptology. Chairs' Symposium dedicated to prevention in epileptology in its broadest sense.
- Interactive session on the use of the proposed ILAE Classification and organization of seizures and epilepsies; ILAE-CEA / European Sleep Research Society joint symposium; Epilepsy Advocacy Europe symposium.
- Two sessions have a special historical perspective: "Unverricht-Lundborg Disease from 1891 to 2014" and "Carbamazepine 50th Year Anniversary Symposium."
- Teaching sessions will feature three attractive morning series run over three days.
- ECE teaching day on last day of congress – full day course "Pharmacological treatment of epilepsy." Two courses targeting epilepsy nurses and EEG technicians; ECE Forums, for interactive discussions focusing on new topics or projects of special interest.
- More time allocated to platform presentations and poster sessions with guided tours and poster highlight sessions.

### Other highlights:

- Nobel theme follows from the London ECE to the home town of Alfred Nobel, with a lecture about the man behind the Prize during the Welcome Ceremony and an exhibit from the Nobel Museum.

## 10th Asian & Oceanian Epilepsy Congress, Singapore 7-10 August 2014



**Organizing Committee:**  
Chairs: Byung-In Lee (Korea), Shih Hui Lim (Singapore)

**Venue:** Grand Copthorne Waterfront Hotel

### Congress program:

- Main session topics: "The chairman's symposium: AED tolerance and resistance"; "Epilepsy burden"; "Neuro-stimulation in the treatment of epilepsy"; "Electrophysiological markers of the epileptogenic zone."
- Practical sessions: Video Quiz; Debates; GCAE Forum; Workshop "Setting up an epilepsy monitoring unit: tips and pitfalls."
- The Masakazu Seino Memorial Lecture: "Recent advances in molecular genetics of epilepsy."
- Series of ASEPA Didactic Lectures each morning.
- New additions: Research Forums – less formal than traditional sessions, in which selected topics can be explored and discussed in a clubroom style; Tournament of the brainwaves.

## 8th Latin American Congress on Epilepsy, Buenos Aires, Argentina 17-20 September 2014



**Organizing Committee:** Chairs: Roberto Caraballo (Argentina), Silvia Kochen (Argentina), Lilia Núñez Orozco (Mexico), Marco Tulio Medina (Honduras)

**Venue:** Hilton Hotel Buenos Aires

### Congress program:

- The Organizing Committee is currently reviewing over 30 session proposals received from ILAE chapters and IBE associations.
- The scientific programme structure will be based on the Quito 2012 layout and will include five ALADE courses and a course planned in conjunction with the newly formed task force on epilepsy in the tropics.
- As in previous congresses, the local IBE association will organize an IBE Epilepsy Day in parallel to the congress.

# INTERNATIONAL DIRECTOR OF MEETINGS REPORT *(continued)*

## 2015

### 31st International Epilepsy Congress, Istanbul, Turkey 6-10 September 2015



#### Organizing Committee:

Congress Chairs: Athanasios Covanis (Greece), Emilio Perucca (Italy)

**Venue:** Istanbul Convention & Exhibition Centre (ICEC)

- The ICEC is close to the center of Istanbul.
- Istanbul has plentiful hotel accommodations across all categories and the city has a good public transport system, with trains, buses and metro. Ferryboats are frequently used to travel between the two sides of the city.
- An open call for session proposals for the 31st IEC was issued with a deadline of end of November 2014.

#### Future Congresses

In addition, the Congress Team is currently working on arrangements for the regional congresses taking place in 2016, as well as the IEC in 2017.

Richard Holmes

*International Director of Meetings*

# ELECTIONS COMMISSION



Peter Wolf, Chair

## Commission Members

Giuliano Avanzini  
Jerome (Pete) Engel  
Natalio Fejerman  
Paul Kioy  
Chong Tin Tan

## RESULTS OF REGIONAL COMMISSION ELECTIONS FOR 2013-2017

### Commission on African Affairs (CAA)



Amadou Gallo Diop, Chair

The election of the four remaining Commission members and appointment of two additional members will take place in 2014.

### Commission on Asian and Oceanian Affairs (CAOA)



Byung-In Lee, Chair

#### CAOA Commission Members (Elected)



Andrew Bleasel



Sunao Kaneko



Leonor Cabral Lim

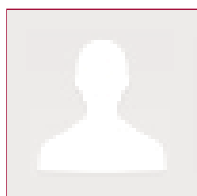


Man Mohan Mehndiratta

#### CAOA Commission Members (Appointed)



Kheng Seang Lim



Guoming Luan



# ELECTIONS COMMISSION *(continued)*

## Commission on Eastern Mediterranean Affairs (CEMA)



Hassan Hosny, Chair

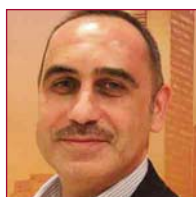


Ahmad Beydoun, Past Chair

## CEMA Commission Members (Elected)



Raidah Al-Baradie



Taoufik Alsaadi



Amina Gargouri



Ahmad Khalifa

## CEMA Commission Members (Appointed)



Ghaieb Aljandeel



Mohammed Al-Shehab

## Commission on European Affairs (CEA)



Meir Bialer, Chair

## CEA Commission Members (Elected)



Sándor Beniczky



Torbjörn Tomson



Eugen Trinká



Matthew Walker

# ELECTIONS COMMISSION *(continued)*

## CEA Commission Members (Appointed)



Annamaria Vezzani



Dana Craiu

## Commission on Latin American Affairs (CLAA)



Marco Medina, Chair



Manuel Campos, Past Chair

## CLAA Commission Members (Elected)



Patricio Abad



Eduardo Barragán



Roberto Caraballo

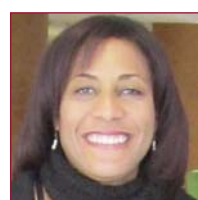


Franz Chaves Sell

## CLAA Commission Members (Appointed)



Laura Guilhoto



Lilia Morales Chacón

# ELECTIONS COMMISSION *(continued)*

## Commission on North American Affairs (CNAA)



Sheryl Haut, Chair

### CNAA Commission Members (Elected)



Nathalie Jette



Jose Cavazos

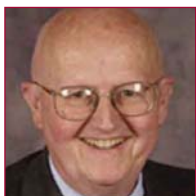


Jaideep Kaipur

### CNAA Commission Members (Appointed)



Dave Clarke



Vicente Iragui

# NEW EXECUTIVE COMMITTEE 2013-2017



Emilio Perucca  
President



Tatsuya Tanaka  
Vice President



Helen Cross  
Secretary General



Sam Wiebe  
Treasurer



Solomon Moshé  
Past President



A. Gallo Diop  
Commission on  
African Affairs



Byung-In Lee  
Commission on Asian  
and Oceanic Affairs



Hassan Hosny  
Commission on  
Mediterranean Affairs



Meir Bialer  
Commission on  
European Affairs



Marco Medina  
Commission on Latin  
American Affairs



Sheryl Hault  
Commission on North  
American Affairs



Gary Mathern  
*Epilepsia*  
Editor-in-Chief



Astrid Nehlig  
*Epilepsia*  
Editor-in-Chief



Athanasios Covanis  
IBE President



Sari Tervonen  
IBE Secretary-  
General



Robert Cole  
IBE Treasurer

## Invitees



Alexis Arzimanoglou  
*Epileptic Disorders*  
Editor-in-Chief



Edward Bertram  
Information  
Officer



Jaime Carrizosa  
Education  
Commission



Jean Gotman  
Director of  
Interactive Media



Torbjörn Tomson  
Strategic Plan  
Committee



# Task Force Reports 2009 – 2013



# PAHO STRATEGY AND PLAN OF ACTION ON EPILEPSY: JULY 2012 TO JUNE 2013



Marco T Medina



Jorge Rodriguez



Carlos Acevedo

During July 2012 to June 2013 several important activities were made on the PAHO Strategy and Plan of Action on Epilepsy:

**1. PAHO/ILAE/IBE Cooperation Agreement:** On November 14-17, 2012 Ecuador hosted the VII Latin American Epilepsy Congress that was sponsored by the International League Against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE). The event served as a framework for the public and official presentation of the *Cooperation Agreement between the Pan American Health Organization (PAHO/WHO), ILAE and IBE*, established to jointly support the implementation of the Strategy and Plan of Action on Epilepsy — approved by PAHO Directing Council in September 2011. Jorge Rodríguez, PAHO/WHO Senior Advisor on Mental Health; Nico Moshé, ILAE's President; and IBE's President, Mike Glynn, participated in the opening panel and presented the agreement. The agreement had been officially signed by Dr Mirta Roses Periago, PAHO Director in Washington DC on October 25, 2012, and during the Congress by Nico Moshé and Mike Glynn.



Quito ceremony of the PAHO/ILAE and IBE Cooperation Agreement: Carlos Acevedo, Marco T Medina, Mike Glynn, Jorge Rodriguez, Nico Moshé and Patricio Abad-Herrera

They were accompanied by: Patricio Abad-Herrera, President of the Congress Organizing Committee; Carlos Acevedo (IBE); and Marco T. Medina (ILAE). Celia Riera, PAHO/WHO Representative in Ecuador, was also present at the event. The authorities and Conference participants celebrated PAHO Strategy and the signed agreement as regional milestones in the field of epilepsy.

## 2. Workshop and Task Force meeting during the VII Latin American Epilepsy Congress in Quito, Ecuador:

During the VII Latin American Epilepsy Congress November 14-17, 2012 in Quito there were two other activities: a workshop on the current situation of the Strategy and Plan of Action on Epilepsy at the country level, and the perspectives on its implementation; and a PAHO-ILAE-IBE Task Force meeting to discuss an agreement-based joint work plan for 2013.

## 3. Planning of the Regional Workshop on Epilepsy in Santiago, Chile:

PAHO/ILAE and IBE planned a Regional Workshop on Epilepsy on "Epilepsy in Latin America: success stories and lessons learned" in Santiago de Chile August 9-10, 2013. The workshop's main objectives are to discuss successful experiences and lessons learned in selected Latin American countries, with emphasis on primary care, thus contributing to the implementation of the Strategy and plan of action on epilepsy in Latin America, and establishing priorities for action. Representatives from several countries were invited: Argentina, Brazil, Chile, Colombia, Honduras, Mexico and Uruguay, as well as representatives from WHO and the ILAE North American Commission.

# EPILEPSY ADVOCACY EUROPE



Mike Glynn



Emilio Perucca



Asla Pitkänen

## Task Force Co-Chairs:

Mike Glynn  
Emilio Perucca

## Task Force Members:

Asla Pitkänen (Secretary)  
Hanneke de Boer (Treasurer)  
Reetta Kälviäinen  
Janet Mifsud  
Michel Baulac  
Christian Elger

## Attending EAE Meetings:

Ann Little (IBE Office)  
Eoin Sheanon

## 1. Meetings and teleconferences

1. August 3, 2012 – EAE meeting, Dublin
2. August 3, 2012 – Scientific Advisory Committee Meeting for the European Forum on Epilepsy Research, Dublin
3. October 3, 2012 – EAE meeting, London ECE
4. January 2, 2013 – EAE Teleconference
5. February 5, 2013 – EAE meeting, London
6. February 26, 2013 – EAE Teleconference
7. March 3, 2013 – EAE Teleconference
8. May 25-27, 2013 – ERF, Dublin
9. June 26, 2013 – EAE meeting, Montreal IEC

## 2. Activities

### 2.1. EAE Symposium in London ECE

What the professionals need to know to improve healthcare and research

Time: Tuesday, October 2, 2012  
02:30 PM - 04:00 PM

Room: Hall 7

Chairs: Emilio Perucca and Mike Glynn

What is the best political agenda for epilepsy in Europe?

Speaker: N. Deva, MEP

Epilepsy in European health care agendas: cost vs. outcomes

Speaker: T Tomson, Sweden

Epilepsy in EU research agenda

Speaker: P. Cupers, DG Research & Innovation, Health Directorate

## 2.2. Epilepsy Research Forum, Dublin 2013 (ERF2013)

- Speaker's presentations  
<http://www.epilepsyadvocacyeurope.org/european-forum-on-epilepsy-research/speakers-presentations.369.html>
- May 25-27, 2013. Overview of the ERF 2013 was published (Sheanon E, Pitkänen A. Epilepsy on the horizon: Dublin forum focused on epilepsy care and research in Europe. *Epilepsia* 2013;54(10):1713-4).
- Output document being prepared by the newly nominated EAE

## 2.3. Web page and Newsletter

- <http://epilepsyadvocacyeurope.wordpress.com/>

## 2.4. European Epilepsy Day

- February 18, 2013 in Brussels
- "Prevalence and Costs of Epilepsy" workshop in European Parliament hosted by Gay Mitchell, MEP

## 2.5. Responses to EU Consultation

- [http://ec.europa.eu/research/consultations/life\\_science\\_h2020/consultation%5Fen.htm](http://ec.europa.eu/research/consultations/life_science_h2020/consultation%5Fen.htm)

## 2.6. Participation in Europeanwide research policy meetings

- Polish EU Presidency
- European Month of the Brain (May 2013) Meetings in Brussels and Dublin

# SPORT AND EPILEPSY TASK FORCE



Pippo Capovilla

## **Task Force Chair:**

Pippo Capovilla (Italy)

## **Task Force Members:**

Ricardo Mario Arida (Brazil)

Alexis Arzimanoglou (France)

Terry O'Brien (Australia)

Ken Kaufman (USA)

Najib Kissani (Morocco)

The Task Force was born during the summer of 2011, before the Rome IEC.

The first Task Force meetings were in Rome where the Photography Sport Project has been launched. The aim was to create a collection of images of famous sports persons willing to be photographed preferably with children, teenagers or young adults with epilepsy. The photographs convey the message that celebrities have no prejudice against the disease and that people with epilepsy can achieve their goals, lead a full and active life and engage in sports.

More than 150 photos of about 60 different sports have been collected. The sport personalities present in the collection are mainly Olympic or World Championship medallists. The first exhibition was held at the recent ECE in London; other exhibitions were at the 7th Latin American Epilepsy Congress in Quito, Ecuador; the Annual Meeting of the American Epilepsy Society in San Diego; in the European Parliament in Brussels, Belgium, for the 3rd European Epilepsy Day; and the 30th International Epilepsy Congress in Montreal.

A book will be distributed to the delegates at the Montreal IEC

## **Task Force Future Activities**

1. To increase the visibility of the Photography Sport Project having the participation of other famous top level sport personalities.
2. To prepare a position paper containing the ILAE official opinion about the medical and legal issues for the practice of sport for PWE.

# ILAE TRANSLATIONAL RESEARCH TASK FORCE



Michele Simonato



Terence O'Brien

## Task Force Co-Chairs:

Michele Simonato and Terence O'Brien

The goals of this task force are to optimize and accelerate preclinical anti-epileptic therapy (AET) development by:

- (a) Formulating precise terminology and identifying optimal methods and strategies for the discovery, validation, and translation of new therapies into the clinics;
- (b) Recommending infrastructure developments that optimize the utilization of resources that can accelerate the discovery and validation of AETs and their clinically relevant biomarkers.

Since 2011, the work of this ILAE Task Force has been a partnership with the American Epilepsy Society (AES) Translational Research Working Group Chaired by Aristea Galanopoulou and Jackie French.

The motivation for the formation of this task force is the concern that, despite the significant advances and introduction of many anti-seizure drugs into the clinical practice, there has been minimal impact on several key unmet therapeutic needs for people with epilepsy. In particular these unmet needs are drug-resistant seizures and anti-epileptogenic/disease-modifying therapies for epilepsies and their comorbidities. It is recognized that changes in traditional pre-clinical development pathways for anti-epileptic therapies are needed if truly transformational new therapies, that address these unmet needs, are to successfully be developed for clinical use. The significant activities of the Translational Research Task Force from July 2012 through June 2013 are outlined below:

## 1. Joint ILAE/AES London Workshop to optimize preclinical epilepsy therapy discovery

This workshop was held 27 - 29 September 2012 in London, UK, prior to the European Congress of Epileptology. The purpose of the workshop was to identify and recommend optimal methodologies, strategies and infrastructure developments to accelerate and de-risk the discovery, validation, and translation of preclinical discoveries into clinically successful therapies for seizures, epilepsies and their comorbidities. The workshop was organized by Drs French, Galanopoulou, O'Brien, and Simonato, attended by 49 international investigators, and was made possible through the generous co-sponsorship by the ILAE, AES, CURE, Epilepsy Therapy Project, and Autism Speaks. The active participation of Drs Whittemore, Fureman, and Ranganathan was also valuable in interfacing with the parallel initiatives from NINDS. Other contributors included: Alexis Arzimanoglou, Kevin Bath, Elinor Ben-Menachem, Ann Berg, Edward H. Bertram III, Amy Brooks-Kayal, Jim Cloyd, Andrew Cole,

Stephen Collins, Mark Dichter, Tracy Dixon-Salazar, Ed Dudek, Jerome Engel Jr, Dan Friedman, Brandy Fureman, Greg Holmes, John Huguenard, Frances Jensen, Rafal Kaminski, Andres Kanner, Jaideep Kapur, Henrik Klitgaard, Merab Kokaia, Holger Lerche, Jeffrey Loeb, Wolfgang Loescher, John Messenheimer, Istvan Mody, Solomon L Moshé, Astrid Nehlig, Jeffrey L Noebels, Manisha Patel, Emilio Perucca, Asla Pitkänen, Roger Porter, Michael Privitera, Jong Rho, Robert Ring, Michael Rogawski, Dieter Schmidt, Graeme Sills, Daniel Smith, Helen Scharfman, Kevin Staley, Eugene Trinka, Elisabetta Vaudano, Annamaria Vezzani, Matthew Walker, Steve H White, Samuel Wiebe, and Karen S Wilcox.

The participants had been organized into seven working groups which had prepared background discussion documents prior to the conference. At the conference each working subgroup presented its summary presentation and proposal followed by group discussions. The working groups were:

1. Defining the clinical "gaps to care" and the "opportunities" to develop new treatment approaches for epilepsy (Chair: J French).
2. General technical and methodological issues in AET development (Chair: A Galanopoulou).
3. Issues related to development of new anti-seizure treatments (Chair: Karen S Wilcox).
4. Issues related to development of anti-epileptogenic therapies (Chair: A Pitkänen).
5. Issues related to symptomatic and disease modifying treatments affecting comorbidities (Chair: A Brooks-Kayal).
6. Issues related biomarkers and surrogate endpoints (Chair: J Engel).
7. Issues related to "Stage II pre-clinical trials" and criteria to propose candidates for clinical trials (Chairs: M Simonato and T O'Brien).

Incorporating the inputs from the general discussion, following the workshop each working group wrote a position paper which were published in a dedicated supplement of *Epilepsia* in 2013 (see below).

Invited speakers from the pharmaceutical industry and funding agencies were also incorporated in the program. Henrik Klitgaard (UCB S.A.) discussed the expectations of the pharmaceutical industry as well as strategies to de-risk the anti-epilepsy drug discovery for seizures and epilepsy syndromes in need of better therapies. Elisabetta Vaudano (Innovative Medicine Initiative (IMI)) presented an overview of the IMI model of public-private partnerships to support drug development. Rajesh Ranganathan (National Institute of

# ILAE TRANSLATIONAL RESEARCH TASK FORCE *(continued)*

Neurological Disorders and Stroke [NINDS]) gave an overview of the current state of funding of translational studies in epilepsy, as well as the history and future goals for the Anticonvulsant Screening Program of the NINDS.

After a general panel discussion, the workshop agreed on the following vision for translational research in epilepsy: *To develop transformational new treatments for people with epilepsy that address the current major clinical gaps in care by 2025, in particular:*

1. *Anti-epileptogenic and disease-modifying treatments*
2. *Drug resistant seizures*
3. *Therapies for comorbidities.*

Five primary next steps were identified to achieve this vision:

1. Develop standards for seizure and comorbidity classifications in animal models.
2. Undertake a systematic review of data from specific animal model data for particular clinical syndromes, including treatments, biomarkers and comorbidities through a Cochrane collaboration.
3. Develop a central database of EEG recordings and interpretation from animal models.
4. Formulate a system for publishing results of negative pre-clinical studies.
5. Work with government funding organizations (NIH and EC) to fund the establishment of a central infrastructure for undertaking multicenter pre-clinical studies to produce higher quality evidence of efficacy of new treatments and targets. This is likely to require the involvement of industry and philanthropic foundations in a partnership with academia and government.

## **2. Epilepsia Supplement on joint AES/ILAE translational workshop to optimize preclinical epilepsy research (Epilepsia 2013; 54(Suppl. 4): 1-74)**

The purpose of this supplement was to report the outcomes of the "London Workshop" and to provide discussion documents for the international epilepsy and drug development community on the critical aspects of translational research addressed by these working groups. The supplement consisted of an article by each of the working groups, and a cover article by the workshop organizers. Each article underwent peer-review prior to being accepted for publication:

1. *Joint AES/ILAE translational workshop to optimize preclinical epilepsy research.* Aristeia S Galanopoulou, Michele Simonato, Jacqueline A French, Terence J O'Brien.
2. *Development of new treatment approaches for epilepsy: Unmet needs and opportunities.*

Jacqueline A French, H Steve White, Henrik Klitgaard, Gregory L Holmes, Michael D Privitera, Andrew J Cole, Ellinor Quay, Samuel Wiebe, Dieter Schmidt, Roger J Porter, Alexis Arzimanoglou, Eugen Trinka, Emilio Perucca.

3. *Epilepsy therapy development: Technical and methodologic issues in studies with animal models.* Aristeia S Galanopoulou, Merab Kokaia, Jeffrey A Loeb, Astrid Nehlig, Asla Pitkänen, Michael A Rogawski, Kevin J Staley, Vicky H Whittemore, F Edward Dudek.
4. *Issues related to development of new antiseizure treatments.* Karen S Wilcox, Tracy Dixon-Salazar, Graeme J Sills, Elinor Ben-Menachem, H Steve White, Roger J Porter, Marc A Dichter, Solomon L Moshé, Jeffrey L Noebels, Michael D Privitera, Michael A Rogawski.
5. *Issues related to development of antiepileptogenic therapies.* Asla Pitkänen, Astrid Nehlig, Amy R Brooks-Kayal, F Edward Dudek, Daniel Friedman, Aristeia S Galanopoulou, Frances E Jensen, Rafal M Kaminski, Jaideep Kapur, Henrik Klitgaard, Wolfgang Loscher, Istvan Mody, Dieter Schmidt.
6. *Issues related to symptomatic and disease-modifying treatments affecting cognitive and neuropsychiatric comorbidities of epilepsy.* Amy R Brooks-Kayal, Kevin G Bath, Anne T Berg, Aristeia S Galanopoulou, Gregory L Holmes, Frances E Jensen, Andres M Kanner, Terence J O'Brien, Vicky H Whittemore, Melodie R Winawer, Manisha Patel, Helen E Scharfman.
7. *Epilepsy biomarkers.* Jerome Engel Jr, Asla Pitkänen, Jeffrey A Loeb, F Edward Dudek, Edward H Bertram III, Andrew J Cole, Solomon L Moshé, Samuel Wiebe, Frances E Jensen, Istvan Mody, Astrid Nehlig, Annamaria Vezzani.
8. *Proposal for a "phase II" multicenter trial model for preclinical new anti-epilepsy therapy development.* Terence J O'Brien, Elinor Ben-Menachem, Edward H Bertram III, Stephen D Collins, Merab Kokaia, Holger Lerche, Henrik Klitgaard, Kevin J Staley, Elisabetta Vaudano, Matthew C Walker, Michele Simonato.

## **3. Other publications related to the work of the Task Force**

Simonato M, French F, Galanopoulou AS, O'Brien TJ. Issues for new antiepilepsy drug development. *Current Opin in Neurology* 2013;26:195-200.

Michele Simonato, Amy R Brooks-Kayal, Jerome Engel Jr, Aristeia S Galanopoulou, Terence J O'Brien, Asla Pitkänen, Karen S Wilcox, Jacqueline A French. *The challenge and promise of*



# ILAE TRANSLATIONAL RESEARCH TASK FORCE *(continued)*

*preclinical therapy development for epilepsy. Invited to resubmit to Lancet Neurology.*

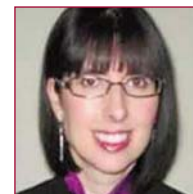
## **4. Liaison with UK NC3Rs Survey on Animal Models Used in Epilepsy Research**

The National Centre for the Replacement, Refinement & Reduction of Animals in Research (NC3R) of the UK has begun an initiative to assess current practices using animal models for epilepsy research, and to formulate recommendations. It was recognized that there was potential for overlap with the work of the ILAE/AES Translational Research Task Force. In order to address this a teleconference was held between the Task Force chairs and the NC3R on August 29, 2013. The outcome of this meeting was a resolution to ensure there was communication between the work of the two groups. Michele Simonato was nominated to represent the Task Force on the NC3R committee.

## **5. Planning toward addressing the “Next Steps”**

A meeting was held of the joint ILAE/AES Translational Task Force at the American Epilepsy Society Meeting in San Diego, December 2012, and at the International Epilepsy Conference in Montreal, June 2013 to begin formulating plans to address the next steps identified at the “London Conference” (see above). Working groups were nominated to address each step, but after discussion with the ILAE leadership it was decided that the final formation of these working groups should wait until the new Commissions and Task Forces were established after July 2013. The members of the new ILAE Task Force nominated are: Terence O’Brien, Michele Simonato (Co-chairs), Marco de Curtis (as Chair of Neurobiology), Akio Ikeda and Asla Pitkänen. It was also decided that the work of the Task Force should be done in partnership with the AES Translational Research Working Group, with Aristeia Galanopoulou and Jackie French nominated by the AES as chairs. The new joint ILAE/AES Task Force will meet at the American Epilepsy Society Meeting in Washington in December 2013.

# EPILEPSY GUIDELINES TASK FORCE



Nathalie Jetté

## **Task Force Chair:**

Nathalie Jetté (Canada)

## **Task Force Members:**

Jo Wilmschurst (Africa)  
Nobukazu Nakasato (Japan)  
Yuping Wang (China)  
Sanjeev Thomas (India)  
Colin Dunkley (UK)  
Emilio Perucca (Italy)  
Eva Kumlien (Sweden)  
Jozsef Janczy (Hungary)  
Horacio Senties (Latin America)  
Sam Wiebe (Canada)  
Khara Savro (PhD student) (Canada)  
Tim Pedley (USA)  
Solomon Moshé (USA)

## **Objectives:**

1. Systematic review of published epilepsy-related guidelines
2. Identification of gaps in guidelines
3. Recommendations regarding which guidelines need to be updated

## **Systematic Review:**

This task force has completed the search (7 databases and 6 grey literature sources) to identify epilepsy/seizure related clinical guidelines in all languages.

- 9766 abstracts have been screened in duplicate with 359 full text articles (13 languages) also screened in duplicate for eligibility.

To date, 79 guidelines have met inclusion criteria to be included for data abstraction. Data abstraction has begun (December 2013) and should be completed by March 2014. Final report expected to be ready by summer 2014.

## **Guidelines Symposium:**

Dr Timothy Pedley chaired a symposium called "Guidelines: the good, the bad and the ugly" at the IEC in Montreal. Speakers included:

1. T. Otsuki (Japan) – Guidelines on epilepsy surgery of the American Academy of Neurology – inform decisions and improve outcomes: Pro
2. H. Cross (UK) – Guidelines on epilepsy surgery of the American Academy of Neurology – inform decisions and improve outcomes: Cons
3. C. Guerreiro (Brazil) – Choice of AEDs by the ILAE guidelines – inform decisions and improve outcomes: Pro
4. J. Wilmschurst (South Africa) - Choice of AEDs by the ILAE guidelines – inform decisions and improve outcomes: Cons

## **Dissemination of Results/End of Term Plan:**

The current work of the guidelines task force began at the end of 2012 and will be ongoing through 2014. This task force has had four in-person meetings and five conference calls. The results of the systematic review being undertaken by the Epilepsy Guidelines Task Force will provide the foundation for a newly formed task force on Epilepsy Guidelines, which will provide guidance on methodology for future development of guidelines for epilepsy. Dissemination of results for initial activities is anticipated through manuscript submission to *Epilepsia*, and presentation (venue to be determined).

# SEIZURES AND EPILEPSY IN THE TROPICS TASK FORCE

## Task Force Chair:

Pierre-Marie Preux (France)

## Task Force Members:

Charles Newton (UK)  
Erich Schmutzhardt (Austria)  
Gretchen Birbeck (USA)  
Peter Odermatt (Switzerland)  
Arturo Carpio (Ecuador)  
Hasan Aziz (Pakistan)  
Dismand Houinato (Benin)  
Helen Cross, Global Outreach Task Force  
Sangeeta Ravat (India)  
Donna Bergen, (USA)  
Esper Cavalheiro (Brazil)  
Phetvongsinh Chivorakul (Laos)

ILAE strongly reaffirmed its will to contribute to decrease the burden of epilepsy worldwide, in particular where this burden is greatest, i.e., in tropical areas. ILAE promoted in 2011 a multidisciplinary new task force on epilepsy in the tropics with the following aims, in conjunction with other recent or previous initiatives.

## Objectives:

- To gather people involved in the field of epilepsy in tropical areas, including those not yet involved in ILAE activities
- To assess specific issues related to this subject, in particular concerning etiologies, socio-cultural aspects and management
- Working with the Global Outreach Task Force, to provide inputs to the ILAE Executive Committee, and to the ILAE Education Commission on initiatives related to epilepsy and seizures in the tropics
- To propose research and/or interventional projects (including comparative studies involving different tropical regions or tropical and non-tropical regions) to raise new hypotheses or test new models for prevention, diagnosis and management of epilepsy in the tropics
- To liaise with the Education Commission in surveying educational needs in the tropics and advising on how best to address them.

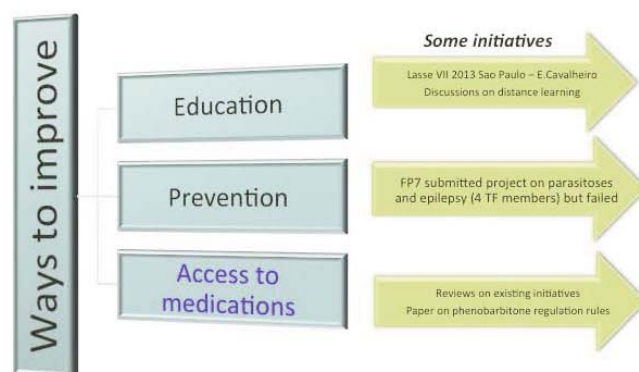
## Means:

- Regular discussions through teleconferences or meetings
- Establishing links with other ILAE task forces or commissions

- Enlisting the collaboration of experts depending on issues being addressed
- Facilitating communication with other partners and institutions

## Outcomes:

- **ILAE clarified objectives of the task force:**  
Focus is tropical and resource poor countries, and should propose ways to:
- Improve access to medication (treatment, case-management, etc.)
- Improve education
- Improve prevention of epilepsy in these settings



## Results:

- Paper submitted on “Undue regulatory control on phenobarbital — an important yet overlooked reason for the epilepsy treatment gap — an urgent call for meaningful action”
- LASSE VII February 2013 (Sao Paulo, Brazil – E Cavalheiro): Seizures and Epilepsies in the tropics
- Parasitel: Research proposal submitted to EU FP7 (but rejected): Parasites and epilepsy (PM Preux, and eight european partners)
- ÉCLAIR: Research program on access to care in Cambodia and Laos (PM Preux)

## To be conducted:

Review of literature on the issue of prevention

# DEFINITION OF EPILEPSY TASK FORCE



Robert Fisher

## **Task Force Chair:**

Robert Fisher (USA)

## **Task Force Members:**

Carlos Acevedo (Chile)  
Alexis Arzimanoglou (France)  
Alicia Bogacz (Uruguay)  
Helen Cross (UK)  
Christian Elger (Germany)  
Jerome (Pete) Engel, Jr (USA)  
Jacqueline French (USA)  
Mike Glynn (Ireland)  
Dale Hesdorffer (USA)  
Byung-In Lee (South Korea)  
Gary Mathern (USA)  
Soloman Moshé (USA)  
Emilio Perucca (Italy)  
Ingrid Scheffer (Australia)  
Torbjörn Tomson (Sweden)  
Masako Watanabe (Japan)  
Sam Wiebe (Canada)

The ILAE convened a Definitions Task Force to come to a consensus on the definition of epilepsy, and whether it should in some circumstances vary from the traditional definition of epilepsy as two unprovoked seizures occurring more than 24 hours apart.

The Task Force reaffirmed the usual “two unprovoked seizure definition,” but suggested a broadening of the definition in three areas. First, some clinicians consider epilepsy to be present in a patient with one seizure and a very high chance of having another. In this context, a very high chance is set as comparable to the risk of a 3rd seizure after having two unprovoked seizures, which is 59-87%. This is viewed as an “opt-in” definition which does not require a clinician to know or estimate future risks in any circumstance, but rather to allow defining a condition as epilepsy after one seizure when such risks are known. Secondly, epilepsy is considered to be “no longer present” after 10 years (five years is still also under consideration) seizure-free.

The Task Force chose a bland new phrase to sidestep assumptions about “cure” or “remission.” Thirdly, reflex epilepsies such as photosensitive epilepsy are clarified to be in the family of epilepsy even though the seizures are provoked by a sensory stimulus. Reflex epilepsies encompass an abnormal ongoing predisposition to respond to a stimulus with a seizure.

The manuscript on the modified definition has received initial favorable review from *Epilepsia*. It is simultaneously undergoing a new process of public posting and comment, which drew 313 comments. Most of these were positive, but some very thoughtful comments were negative. A second task force is considering how to incorporate the essence of the public comments into the final manuscript. This second task force consists of Robert Fisher, Helen Cross, Gary Mathern (who is recused from the *Epilepsia* deliberations), Lars Forsgren, Angelina Kakooza and Akio Ikeda. After all revisions are taken and the manuscript drafted in penultimate form, the ILAE Executive Committee will vote on whether to adopt the revised definition as an official ILAE position.

# STIGMA TASK FORCE



Nathalie Jetté

## Task Force Chair:

Nathalie Jetté (Canada)

## Task Force Members:

Gretchen Birbeck (USA)  
Manjari Tripathi (India)  
Helen Cross (UK)  
Ann Jacoby (UK)  
Hanneke de Boer (Netherlands)  
Janet Mifsud (Switzerland)  
Tarun Dua (Switzerland)  
Patricia Braga (Uruguay)  
Paula Fernandes (Brazil)  
Kirsten Fiest (Canada)  
Diane Lorenzetti (Canada)  
Samuel Wiebe (Canada)  
Amza Ali (Jamaica)  
Joan Austin (USA)  
Solomon Moshé (USA)  
Karen Parko (USA)

## Objectives:

1. To carry out an up-to-date international systematic review focusing on epilepsy-related stigma: Tools to measure it, frequency and nature of stigma, and interventions to address it.
2. To make recommendations regarding gaps and future research needs in the area of epilepsy-related stigma.

## Systematic Review:

The Stigma Task Force has screened 4,123 abstracts in duplicates from 13 databases (all languages), reviewed 821 articles to determine their eligibility for data abstraction and have completed the initial data abstraction (study demographics/region, topic addressed, age groups, etc.) for just over 300 articles (38 addressing tools used to identify stigma, 284 addressing the frequency and nature of stigma and factors associated with it and 28 addressing interventions for stigma). Data abstraction began in spring 2013 with initial results presented as a platform

session at the IEC in Montreal in June 2013. Full data abstraction in duplicate is expected to be completed by spring 2014 with several manuscripts/reports to be written spring/summer 2014.

## Stigma Symposium:

ILAE meeting, Montreal 2013. The symposium proposal submitted jointly by NAC and the Commission on Stigma was accepted for the upcoming Montreal meeting, chaired by Dr Jetté. Main Session: Stigma in epilepsy — who, why and what to do? Speakers:

1. Nathalie Jetté (Canada) – Introduction to stigma and symposium topics/speakers
2. Paula Fernandes (Brazil) – Assessing stigma: Do we know it when we see it?
3. Ann Jacoby (UK) – Stigma: Why some people and not others?
4. Gretchen Birbeck (USA/Africa) – Reducing stigma: Can it be done?
5. Nathalie Jetté (Canada) – A future without stigma and conclusions
6. Panel discussion

Dissemination of results/end of term plan: The current work of the Stigma Task Force will be ongoing through 2013 and 2014. Dissemination of results is anticipated through presentation at the symposium in Montreal 2013 followed by manuscript submission to *Epilepsia* (3-4 manuscripts) in 2014.





# Regional Commissions 2009 – 2013

# COMMISSION ON AFRICAN AFFAIRS



Amadou  
Gallo-Diop

## Commission Members:

Chair	Amadou Gallo-Diop (Senegal)
Secretary General	Callixte Kuate Tegueu (Cameroon)
Treasurer	Angelina Kakooza (Uganda)
Education Officer	Jo Wilmshurst (South Africa)
Research Officer	Paul Kioy (Kenya)
Communication Officer	Birinus Ezeala Adikaibe (Nigeria)
Liaison to GCAE (Outreach)	Baba Koumare (Mali)

## Subcommissions and Members Task Force on Access to Care:

Sammy Ohene, Ghana  
Amara Cisse, Guinea

## Aims

- To set up the organization of the Commission on African Affairs
- To strengthen the communication and ILAE global outreach campaign of the CAA
- To establish and strengthen the education activities of the CAA
- To improve the access to care for patients with epilepsy
- To establish and coordinate epilepsy-related research activities in the African continent.

## Mission of the Commission

The ILAE Commission on African Affairs shall serve all health professions in Africa as the premier international resource for current and emerging knowledge on epilepsy prevention, diagnosis, treatment, and research.

## Commission Activities from July 2009 through July 2013

- February 10-11, 2013: workshops organized by the Association of Child Neurologists in Africa (ACNA) in Cape Town, South Africa. The theme of the congress was cerebral palsy and epilepsy. See reports and publications on CAA Newsletter / [www.ICNAPedia.org](http://www.ICNAPedia.org).
- May 2013: Publication of the third version of the CAA newsletter.
- June 23-27, 2013 in Montreal, Canada (Palais de congrès): CAA Executive meeting. The agenda focused on: Dakar-Senegal francophone training program 2013, Training programs in Africa - short courses, formal training - adult, pediatric, and neurophysiology (capacity, curriculums, African relevance etc.), Capacity - the way forward -

consensus of how to offer support to structure, Equipment (what to do with old equipment offered to Africa) - need a policy/statement from CAA of best practice, Visiting programs - how is it going - good for CAA to build these - feedback on last year's ones and plans for 2013/2014 - CAE and NAA, Courses - how can CAA get involved with neurology courses in Africa, what are the guidelines to support junior trainees to attend international courses, 4th newsletter and CAA website, Where are we? How can we improve? Research in epilepsy: What can we do? Needs? Difficulties? How to increase the capacity of training centers? How can we improve communication amongst members? ILAE officers? How to increase African ILAE chapters, 2nd African Epilepsy Congress 2014 (date, venue, organization) and Elections of the ILAE/CAA officers.

- July 11 – 13, 2013: Francophone Epilepsy workshop in Dakar, Senegal. In collaboration with WFN/EFNS/IBRO/ICNA. We had international and African speakers on adult and pediatric epilepsy. African francophone countries like Mali, Niger, Senegal, Côte d'Ivoire, Guinea, Mauritania, Togo, Benin, Cameroon, and Central African Republic were represented. Three speakers came from the ILAE/North American Commission. This course was originally planned for Bamako, Mali, however due to logistical reasons has been deferred to Dakar, Senegal.
- From August 2013: Updating the document Epilepsy in the WHO African region. WHO-AFRO has already received the first draft of the revised document.
- Award of a bursary from the CAA to support the development of an epilepsy training center: Diploma in Pediatric Electrophysiology and Management of Epilepsy in Children (South Africa).
- Award of a bursary from CAA to support the development of an epilepsy training center: interactive internet-based teaching platform for CME in Clinical Neurophysiology in Sub-Saharan Africa (South Africa).

## Accomplishments (2009-2013)

- Organization of the 2nd African Epilepsy Congress in Cape Town, South Africa, May 22-24, 2014
- Admission of new members in the ILAE African region during the ILAE General Assembly in Montreal, Canada: Ivory Coast, Rwanda and Democratic Republic of Congo.

# COMMISSION ON AFRICAN AFFAIRS *(continued)*

## **Recommendations for Future Work**

- Increase the number of African ILAE chapters
- Regular publication of the regional IBE and ILAE/CAA newsletter
- Update the GCAE document in French, English and Portuguese
- Regular organization of epilepsy training courses in French, English and maybe Portuguese
- Elaborate guidelines for management of seizures for African neurologists, GPs and allied medical professionals.

## **New Commission Members (2013-2017)**

Amadou Gallo Diop, Chair (Senegal)

The election of the four commission members and appointment of two additional members will take place in 2014.

# COMMISSION ON ASIAN AND OCEANIAN AFFAIRS



Byung-In Lee

## List of Members and Officers (Table 1 and 2)

**Table 1. Officers of CAO A (2009-2013)**

Chair	Byung-In Lee (Korea)
Secretary	John W Dunne (Australia)
Treasurer	Jing-Jane Tsai (Taiwan)
Information Officer	Sunao Kaneko (Japan)
Members	Hasan Aziz (Pakistan)
	Shi Chuo Li (China)
	Chong Tin Tan (Malaysia)
	Shih-Hui Lim (Singapore)
Ex-Officio	Tatsuya Tanaka
	(Japan, ILAE – first vice president)
	Vrushali Nadkarni (India)

### Task Forces

1. Research Task Force	Patrick Kwan (Hong Kong)
2. Global Campaign Task Force	Ernest Somerville (Australia)

The Asian Epilepsy Academy (ASEPA) was formed in 2003, initially as the educational arm and now a subcommission of CAO A. The composition of ASEPA is shown in Table 2.

**Table 2. Officers of ASEPA**

<b>(2007-2011)</b>	
Chair	Chong Tin Tan (Malaysia)
Secretary	Andrew Bleasel (Australia)
Members	Gourie Devi (India)
	Yushi Inoue (Japan)
	Weiping Liao (China)
	Shih-Hui Lim
Ex-Officio	Byung-In Lee (Chair, CAO A)
<b>(2011-2015)</b>	
Chair	Shih-Hui Lim (Singapore)
Secretary	Wendyl Souza (Australia)
	Man Mohan Mehndiratta (India)
	Yushi Inoue (Japan)
	Weiping Liao (China)
	Dede Gunawan (Indonesia)
	Josephine Gutierrez (Philippines)
Ex-Officio	Byung-In Lee (Korea, Chair of CAO A)
	Chong Tin Tan (Malaysia, Immediate past president, ASEPA)

## Action Plans of CAO A: 2009-2013

- Construct CAO A website linked with ILAE website and individual CAO A-Chapter websites and publish CAO A-Newsletter** (by Information committee): Achieved as planned
  - CAO A website (<http://www.caoa-epilepsy.org>)
- Published the first CAO A-Newsletter in December 2012
- Enhance educational and training efforts and activities (by ASEPA): Achieved as planned
  - Teaching courses and workshops in regions in need (provides 10 to 12 courses per year)
  - Epilepsy Fellowship for future epilepsy Specialists in the region (provides 2 ASEPA Fellowships/year and another 2-4 Fellowships/year in collaboration with Epilepsy Research Foundation of Japan, Japan Epilepsy Societies, and Epilepsy Society of Australia)
  - Promote skills in EEG recording and interpretation (ASEPA EEG-Certification examinations and EEG teaching courses in collaboration with ANZAN)
  - Publish proceedings of AOEC in Neurology-Asia
- Organize the Asian and Oceanian Epilepsy Congresses every two years: Achieved as planned
  - 8th AOEC in Melbourne in October 2010
  - 9th AOEC in Philippines in March 2012
- Stimulate Clinical and Translational Research (by Research TF): Achieved as planned
  - Stand-alone meeting of Research TF in Taipei in July 2011
  - Preparation of the CAO A-Research Priority document
- Promote New Chapter Formation; Achieved as planned
  - Vietnam in 2009
  - Sri Lanka in 2011
- Facilitate Global Campaign Against Epilepsy Activities (by GCAE TF): Achieved as planned
  - GCAE workshops at the 8th and the 9th AOEC
  - Stakeholders meeting at the 9th AOEC
  - Planning a CAO A-demonstration project for the reduction of treatment gap in Asia
- Facilitate interactions among chapters and commissions: Achieved as planned
  - Joint symposium with Asian Epilepsy Surgery Congress in Hong Kong, 10 November 2011
  - Joint symposium with Infantile Spasm Society in Tokyo, Japan, February 2012

# COMMISSION ON ASIAN AND OCEANIAN AFFAIRS *(continued)*

- (3) Active participation of ASEPA and CAO A with Congresses, summer schools, or Epilepsy Symposia held by individual chapter
- (4) Planning a joint symposium with AOCN in Hong Kong, 2014
- 8. Initiate the Asian and Oceanian Outstanding Achievement Epilepsy Award (AOEA): Achieved as planned
  - (1) First AOE A at the 8th AOEC at Melbourne (2010), 5 award recipients: H Aziz (Pakistan), T Tanaka (Japan), K Yagi (Japan), P Satishchandra (India), X Wu (China)
  - (2) 2nd AOE A at the 9th AOEC at Manila, Philippines (2012), 6 Award recipients: L Cabral-Lim (Philippines), Y Inoue (Japan), S Kaneko (Japan), K Radhakrishnan (India), L Wu (China)

## **New Commission Members (2013-2017)**

Byung-In Lee, Chair (Korea)  
Andrew Bleasel (Australia)  
Leonor Cabral-Lim (Philippines)  
Sunao Kaneko (Japan)  
Kheng Seang Lim (Malaysia)  
Guoming Luan (China)  
Man Mohan Mehndiratta (India)  
Tatsuya Tanaka, EC Liaison (Japan)



# COMMISSION ON EUROPEAN AFFAIRS



Meir Bialer

## Commission Members:

Chair	Meir Bialer (Israel)
Secretary	Alla Guekht (Russia)
Communication Liaison	Alexis Arzimanoglou (France)
Past Chair	Michel Baulac (France)
Treasurer	Eugen Trinkla (Austria)
Global Campaign Liaison	Athanasios Covanis (Greece)
Educational Liaison	Helen Cross (UK)
EAC – European Advisory Council – Secretary	Reetta Kalviainen (Finland)
Ex-Officio, Basic Sciences Liaison	Asla Pitkänen (Finland)
EAC – European Advisory Council – Chair	Torbjörn Tomson (Sweden)
Ex-Officio, EC Liaison	Solomon L Moshé (USA)
Ex-Officio, EC Liaison	Emilio Perucca (Italy)

## CEA Key Accomplishments 2009-2013

- Established the CEA Strategic & Action Plans
- Established an educational agenda available for review on the CEA website with procedures for applications for CEA supported courses/symposia
- Two types of educational courses: CEA-Core Courses (CCC) and CEA-sponsored activities (CSA)
- Promoted Epilepsy Advocacy & Research in Europe (EAE) through a joint ILAE-IBE Task Force (JTF), in partnership with European ILAE chapters and IBE associations
- Subsequently epilepsy research was included in the EU-FP-7 call for grant proposals
- Updated the Bylaws of the European Congress on Epileptology (ECE)
- Updated CEA rules in accordance with the ILAE-EC constitutional amendments
- Established collaboration between the CEA and the ILAE-North American. A joint CEA-CNA symposium at the 2011 & 2013 AES & 2012 & 2014 ECE
- Started a collaboration with the ILAE-CAA (Commission on African Affairs) aiming to answer unmet educational needs in Africa

*Aim 2: Stimulate & enhance education on the prevention, diagnosis & treatment of epilepsy*

### Action

Two types of educational courses:

- CEA-Core Courses (CCC): 1) Clinical Epileptology (Migrating Course-MC); 2) Pharmacology (Eilat Edu); 3) EPODES (Surgery)

- CEA-sponsored activities (CSA): e.g. 1) Basic & Translational Science, Pediatrics (San Servolo); 2) Stereo EEG (Lyon); 3) Regional Courses: Caucasian & Baltic-Sea Summer Schools on Epileptology

*Aim 3: Stimulate and enhance basic and clinical research in epilepsy in Europe*

### Action

Epilepsy Advocacy Europe (EAE): a CEA-EREC Joint Task Force (JTF) for epilepsy advocacy that achieved the following:

- Approval of the Declaration on Epilepsy in the EU Parliament
- Encouraged and supported national CEA/EREC (ILAE/IBE) chapters to obtain a fair allocation of health care resources to epilepsy
- Ensured that epilepsy achieves priority status in the EU framework program for research
- Set up an educational campaign to fight ignorance and stigma, and to improve legislation to protect rights of people with epilepsy
- Organized a conference in Dublin, Ireland on May 25-27, 2013 entitled: "European Forum on Epilepsy Research (ERF2013)" attended by all parties (lay, professional, political) to sensitize them to the above needs
- Catalyzed collaboration on innovative research and demonstration projects

*Aim 4: Work with European organizations to catalogue current epilepsy care in Europe and determine its needs*

### Action

- Annual ILAE-CEA and EFNS joint symposia since 2011
- ILAE-CEA and ESRS joint symposia: 2012-ESRS & 2014-Stockholm-ECE (ESRS - European Sleep Research Society)

*Aim 5: Prompt and facilitate initiatives that improve standards of comprehensive care (diagnosis, treatment and social care). Reduce the treatment gap throughout Europe*

### Action

- A CEA-CNA-CTA Joint Task Force (JTF) on regulatory issues of new AEDs (meeting in Rhodes-ECE, AES-2010, Rome-IEC) and a JTF-EMA-FDA meeting on regulatory issues (Paris 17/11/2011)
- Forthcoming White Papers to the FDA: 1) using add-on therapy for a combined monotherapy/add-on therapy indication; 2) extrapolation of adult partial onset seizure data to children; 3) use of the time to event analysis for pivotal trials

# COMMISSION ON EUROPEAN AFFAIRS

(continued)

*Aim 6: To help ensure that ILAE's organizational structure is efficiently and effectively dedicated to fulfilling ILAE mission*

Action:

- a) Continuous update of European chapters' chairs and secretaries (via Gus Egan ILAE Dublin office)
- b) Establish ILAE chapters in the three remaining European countries (Belarus, Bosnia and Iceland)
- c) Update CEA rules in accordance with the ILAE-EC proposed constitutional amendment
- b) Regional epilepsy educational conferences in European regions with unmet need for epilepsy training
- c) Scientific conferences with European-added values
- d) Writing a European Educational Agenda with criteria for course organizers and bursary applicants for CEA-sponsored courses
- e) Establishing at the ILAE office in Dublin a repository of all participants who received bursaries for CEA-sponsored courses from 2011 on.

## CEA-Sponsored Courses/Symposia in 2013

- a) Advanced Epilepsy Surgery Course (Brno, January 22-26)
- b) 4th Stereo-EEG Course (Lyon, February 12-16)
- c) 4th Colloquium on Status Epilepticus (Salzburg, April 4-6)
- d) A comprehensive course on Epilepsy (Tashkent, April 17-21)
- e) San-Servolo Course on Surgery (Venice, July 14-25)
- f) 7th Baltic Sea Summer School (Estonia, August 17-21)
- g) Neuropathology Summer School (Erlangen, September 16-20)
- h) Surgical Management of Epilepsy (Ljubljana, August 28-30)
- i) Workshop on Improving Care in Epilepsy (Ljubljana, August 27-28)
- j) 5th Eilat Educational Course on Pharmacology (Jerusalem September 30-October 5)
- k) 7th Migrating Course on Epilepsy (Nicosia, November 3-9)
- l) VIREPA-EEG SCORE Course (October 2012-February 2013)

## CEA-Sponsored Events for 2012-2013

- a) A European Chapter Convention during the London-ECE (9/30/2012) and Dublin during ERF2013 (5/25/2013) and thus, having a yearly dialogue between the CEA and the various ILAE-European chapters

## Additional CEA Targets for 2013 and 2014

- a) Making the 11th European Congress on Epileptology (ECE, June 29-July 4, 2014) in Stockholm at least as successful as ECEs in Vienna (2004), Helsinki (2006), Berlin (2008), Rhodes (2010) and London (2012).
- b) Continual update of European chapters' chairs and secretaries
- c) Establish ILAE chapters in the three remaining European countries

## New Commission Members (2013-2017)

Meir Bialer, Chair (France)  
Eugen Trinko (Austria)  
Matthew Walker (UK)  
Sandor Beniczky (Denmark)  
Dana Craiu (Romania)  
Torbjörn Tomson (Sweden)  
Annamaria Vezzani (Italy)  
Emilio Perucca, EC Liaison (Italy)

# LATIN AMERICAN REGIONAL COMMISSION



Manuel Campos

## Commission Members:

Chair	Manuel Campos, Chile
Secretary	Eduardo Barragán (México)
Treasurer	Patricia Braga (Uruguay)
LASSE	Esper Abrao Cavalheiro (Brazil)
	Franz Chaves Sell (Costa Rica)
	Beatriz González del Castillo (Venezuela)
	Salvador González-Pal (Cuba)
	Silvia Kochen (Argentina)
	Magda Nunes (Brazil)

## Subcommissions and Members Task Force on Access to Care:

Marco Medina (Vice-President and EC Liaison, Honduras)  
Alejandro Scaramelli (Ex-Officio, Uruguay)  
Samuel Wiebe (EC Liaison, Canada)

## Aims

1. To provide and promote epilepsy education and research with excellence, quality, efficient and humanistic approach for medical and non-medical professionals in Latin America.
2. To coordinate academic activities among the ILAE Latin American Region Chapters. Eleven physicians compose the Commission, but also all Latin-American ILAE Chapters are involved.

The first meeting was accomplished during the International Epilepsy Congress at Budapest in July 2010. There we established the preliminary plan with the Executive Committee of ILAE.

The Latin American Commission has as an objective to improve the diagnosis and treatment of the epilepsies in Latin America, in the frame of our ILAE politics and its strategic plan.

## Commission Activities from July 2012 through July 2013

Nowadays the Latin American region is living its best moments in epilepsy, but that is not fortuitous; it is the result of several years of work of many people involved in the ILAE (regional commission, executive, LASSE, ALADE, etc.).

The main fact for the regional development is "Education":

- 1) **LASSE (Latin American Summer School in Epilepsy):** for more than seven years Esper Cavalheiro and Brazilian colleagues organize with the support of the Brazilian government and ILAE the main regional meeting for young people and best epilepsy professors in the world. From LASSE each year is coming new generations of

epileptologists for the region. Now we can see many young epileptologists in ILAE chapters.

- 2) **ALADE (Latin American Academy of Epilepsy):** It depends directly our commission and with its leader, Elza Marcia Yacubian (Brazil), and a group of many young colleagues that perform educational activities in different countries (Bolivia, Brazil, Chile, Cuba, Ecuador, Guatemala, Venezuela, etc.), with courses for general physician and specialist, books (semiology and EEG) and videos (EEG). We need to perform more continuous education with other mechanisms, because the budget is limited and also the time of our professors.

- 3) **LACE (Latin American Epilepsy Congress):** Every two years the epilepsy community has the opportunity to meet. There we have also the opportunity of meeting all ILAE chapters. Quito 2012 (president: Patricio Abad) was our VII LACE with great success.

- 4) **Epilepsy fellows in the region:** Our commission has performed the identification of the best and certified "Epilepsy Centers" in Latin America for epilepsy training (clinical, EEG, surgery, etc.). With the support of ILAE we have given more than 12 fellows in the last few years, coming countries with low epilepsy development. After the fellowship they have continued to work in ILAE chapters and the public system.

- 5) **Meeting of Latin American Epilepsy Centers:** Its activity began in 2010 as a small meeting organized in Uruguay (by Patricia Braga), but now with the ILAE support we had our 4th meeting May 2013 in Santiago, Chile. There we had more than 40 epilepsy centers of 14 different countries and 220 participants (120 aren't Chilean). This activity has a different orientation than LACE's in order to create epilepsy consensus and more contact between the different epilepsy groups in the region.

- 6) **New Chapters:** With the special work of Eduardo Barragán, El Salvador and Bolivia are our new ILAE chapters; with these two countries we have the whole region with active chapters. But we have some chapters without democracy, where the same people remain for many years and stop the development of the new epilepsy generations. We, as the Latin-American Regional Commission, don't have the tools for a solution, because each country is independent, but our alternative way is to support the young people with epilepsy interests in these countries.

- 7) **Relationships with North America's sub-commission:** The principal activity is our "Spanish Symposium" each year at the AES Congress, where we have on average 200 assistants. The main sessions at the congress

# LATIN AMERICAN REGIONAL COMMISSION *(continued)*

have simultaneous translation. We have the best educational relationship with our North American partners.

The great challenge: "The Strategy and Plan of Action on Epilepsy": On September 2011 the Pan American Health Organization (PAHO) in its 51st Annual Assembly approved the "Strategy and Plan of Action for Epilepsy" for the Americas.

Between 2011-2012 all ILAE and IBE chapters in Latin America have contact with the local Pan American Health Organization (PAHO), and together have visited the local authorities in the health ministry in order to develop "National Epilepsy Programs" and "Epilepsy Laws" in each country of Latin America.

But now, almost two years from September 2011 we have more political issues than effective actions in direct benefit of our epilepsy patients. Now our challenge is to develop epilepsy programs in all regional countries, and improve the prevention, diagnosis, treatment and quality of life in all people with epilepsy.

To finish I would like to thank all my commission friends, but especially to Patricia Braga (Treasurer), Eduardo Barragán (Secretary), Franz Chaves (Website), Esper Abrao (LASSE) and Elza Marcia Yacubian (ALADE) for their ongoing work and support.

## **New Commission Members (2013-2017)**

Marco Medina, Chair (Honduras)  
Franz Chaves Sell (Costa Rica)  
Roberto Caraballo (Argentina)  
Patricio Abad (Ecuador)  
Eduardo Barragán (Mexico)  
Lilia Morales (Cuba)  
Laura Guilhoto (Brazil)  
Manuel Campos (Chile)  
Samuel Wiebe, EC Liaison (Canada)

# NORTH AMERICAN COMMISSION



Sheryl Haut

## Commission Members:

Chair	Sheryl Haut (USA)
Past Chair	Jacqueline French (USA)
EC Liaison	Samuel Wiebe (Canada)
Treasurer	Lionel Carmant (Canada)
Secretary	Sharon Whiting (Canada)
Education Officer	Jaideep Kapur (USA)
	Amza Ali (Jamaica)
Liaison to Global Outreach	William Theodore (USA)
Information Officer	Nathalie Jetté (Canada)

## Subcommissions and Members Task Force on Access to Care:

Stigma Task Force: Natalie Jetté (Chair) and 14 international members

Education Task Force: Jaideep Kapur (Chair, USA), Sheryl Haut (USA), Jose Cavazos (USA), Nizam Ahmad (Canada), Lionel Carmant (Africa program)

Task Force on Regulatory Harmonization: Members: Jacqueline French (Chair, USA), Meir Bialer (Israel), Steven Schachter (USA) (tri-chairs), Michel Baulac (France), Emilia Bagiella (statistician), Alexi Arzimanoglou (France), Eugen Trinko (Austria), Scott Mintzer (USA), Emilio Perucca (Italy)

Task Force for Caribbean Development: Amza Ali (Chair, Jamaica), Sharon Whiting (Canada, formerly Jamaica), David Clarke (U.S. formerly from Antigua), Lionel Carmant (Canada)

Hispaniola Task Force: Lionel Carmant (Chair, Canada), Marco Medina (Latin American Commission), Diogenes Santos-Viloria (Dominican Republic), Michel Baldy Mouliner (EUREPA), Alex Elie (Haiti), Marcel Sévere (Haiti), Farah Lubin (USA), Jose Ferreira (USA).

PAHO Task Force: Sheryl Haut (Chair, NAC), William Theodore (AES-IAC), Nathalie Jetté (Canada), Jaideep Kapur (USA), Jorge Burneo (Canada)

Institute of Medicine: Sheryl Haut (Chair, NAC); NAC members

## Aims

The Commission established seven task forces to accomplish the stated goals.

## Commission Activities from July 2012 through July 2013

Goal 1: ILAE shall serve all health professions as the premier international resource for current and emerging knowledge on epilepsy prevention, diagnosis, treatment, and research.

- Systematic review of stigma in epilepsy literature — results to be disseminated in *Epilepsia* and Montreal

Systematic review: The Stigma Task Force has nearly completed reviewing 700 full text articles identified by review of 4,123 abstracts related to stigma in epilepsy. Data abstraction began in April 2013 with results anticipated and manuscript preparation planned by spring/summer 2013.

Stigma Symposium: ILAE meeting, Montreal 2013. The symposium proposal submitted jointly by NAC and the Commission on Stigma was accepted for the upcoming Montreal meeting, chaired by Dr. Jetté. Main Session: Stigma in epilepsy: who, why and what to do?

- Translation project - pilot Spanish translation of two symposia at AES, expansion to be explored

Translation was provided for two symposia at AES 2012. The translation units were utilized by a very small number of attendees. The need and future of this program will be discussed with the Latin American Commission in Montreal.

- Visiting professorships – good project for export to other regions

Strengths: Has established enduring collaborations between centers; has effected local change

Challenges: Identifying needs and assessing outcomes; identifying appropriate sites; choosing partnerships with long-term potential

The PECA program has continued to support partnerships between epilepsy centers in the Americas to promote education and improvements in epilepsy care. Over 25 visits have been completed through this program, with more in process. In the current year, the focus has been on funding reverse visits by Latin American faculty to visit North American Centers. The NAC has been working closely with the LAC on a joint project of funding these visits.

This program was more recently extended to Africa, in collaboration with the African Commission. The education task force worked with Dr. Carmant and the African Commission to develop a call for proposals for visiting professorships to Africa, and supported these fellowships. The task force and others reviewed the proposals and selected the top three for funding. These visits took place and three more are planned for 2013.

- Telemedicine

The telemedicine project now exists between Yale and Jamaica, towards the development of an epilepsy surgery program in the Caribbean.



# NORTH AMERICAN COMMISSION *(continued)*

- International symposia/courses

The NAC has established a joint-symposium plan with the EUC. The NAC-AES symposium is shared with the EUC every other year; similarly the EUC symposium at the European Congress is shared with AES every other year. In addition, the NAC has sponsored symposia at the International Epilepsy Congress, and the Regional Caribbean Congresses.

- Regulatory affairs

The task force on regulatory harmonization in collaboration with the European Commission has had a series of meetings with members of the FDA and the EMA. The goal of this effort is to identify and refine the optimal clinical trial methodologies for new anti-epileptic drugs. A seminal meeting took place in Paris in 2011 with a follow up meeting at the Eilat conference in May 2012, focused on three areas: 1. New study design for monotherapy trials, which the FDA is willing to consider; 2. Approval for pediatric age groups when adult trials have been performed for the same indication, which the EMA has accepted and the FDA will consider; 3. Novel "time to event" trial design, which both the EMA and FDA are willing to consider pending new data analysis pooled from multiple studies.

A white paper is in process to propose the elimination of separate indications for monotherapy and add-on therapy. Similarly, a white paper is being considered to present the pediatric approval proposal to the FDA following a meeting (the PEACE meeting) in collaboration with the FDA this fall. It is anticipated that these manuscripts positioned as white papers dealing with these regulatory issues will be submitted by the end of this NAC term. The meeting planned with the FDA for 2013 will help to direct these efforts.

- Neuro-cysticercosis prevalence project – manuscript in late 2012

Phase 2 of the neurocysticercosis project involves testing 125 control subjects with no history of seizures, to match the epilepsy prevalence identified in Phase 1. This work continues but has been slowed due to internal elections.

Goal 2: ILAE shall serve as an international information resource and leader for optimal, comprehensive epilepsy care.

- IOM report – dissemination of recommendations

The NAC, with the ILAE, participated in the release of the IOM report on epilepsy, and has continued to work with IOM Healthcare providers group on the implementation of the IOM recommendations. Most recently, the NAC provided an inventory of activities related to specific IOM recommendations. NAC

members have also been active participants in the epilepsy screening tool initiative, one of the first deliverables of the IOM.

- PAHO initiative – implementation will be a major focus for the NAC during the remaining 18 months of the term.

The PAHO task force of the NAC has been working closely with the PAHO task force of the Latin American Commission, as well as other members representing the ILAE including Drs. Mathern, Beghi and Hesdorffer. Following an initial meeting in 2011, a large meeting took place at the Latin American Congress in November 2012, where the NAC worked in concert with the Latin American Commission, the European Commission, the Epidemiology Commission and the Global Outreach Commissions to help formulate a roadmap for the implementation of PAHO over the coming years. The NAC representatives provided insights into many projects consistent with the PAHO mandate that have been successfully completed during the past two terms. Additionally, the IOM report provided potential examples of regulatory progress in epilepsy care and this will be discussed. As the PAHO epilepsy initiative is in its early stages, it is anticipated that the NAC will continue to be closely involved in PAHO in the coming term, including participation in the PAHO meeting scheduled in Santiago 2013.

- Formation of the Epilepsy Society of the Caribbean

The Caribbean task force, in collaboration with the ILAE executive committee, has been extremely successful in forming a new ILAE chapter, namely the Epilepsy Society of the Caribbean. This chapter received provisional approval by the ILAE, pending ratification by the general assembly in 2013. The announcement of this approval was made at the Caribbean Regional Epilepsy Congress in Antigua 2012, a successful meeting which was attended by health care professionals from 11 Caribbean islands. The NAC supported travel awards for junior Caribbean faculty to attend this congress.

Goal 3: ILAE shall work to ensure its ongoing organizational and financial viability

- Travel support

The NAC has supported travel by Drs. Ali and Clarke to build and develop a clinical epilepsy service in Antigua, an island which previously had no specific epilepsy care. The NAC has also supported travel by Caribbean physicians to the Caribbean Regional Epilepsy Congresses.

- Website development

The NAC website has been updated, but further improvement is planned for the next term.

# NORTH AMERICAN COMMISSION *(continued)*

## Challenge

- Incorporating the work of topic-oriented commissions

The NAC is joining with the Classification Commission and a new ILAE working group towards development of a conversion document for ICD-10.

- Disparities study needs to be done

To be discussed with the new Commission.

## Charge

- Understand the role of the Commission in the implementation of PAHO initiative.

## **Commission Members 2013-2017**

Sheryl Haut, Chair (USA)

Jose Cavazos (Canada)

Jaideep Kapur (USA)

Nathalie Jetté (Canada)

Dave Clarke (USA)

Vincente Iragui-Madoz (USA)

Solomon Moshé, EC Liaison (USA)



# Topic-Oriented Commissions 2009 – 2013

# COMMISSION ON CLASSIFICATION AND TERMINOLOGY



Ingrid Scheffer

## List of Members

Chair	Ingrid Scheffer (Australia)
Secretary, Past Chair	Anne Berg (USA)
Information Officer	Pippo Capovilla (Italy)
Finances	Mary Connolly (Canada)
Education Officer	Sameer Zuberi (UK)
	Laura Guilhoto (Brazil)
	Edouard Hirsch (France)
	Helen (Yue-Hua) Zhang (China)
Ex Officio – Pediatrics	Doug Nordli (USA)
Ex Officio – Genetics	Sam Berkovic (Australia)
EC Liaison	Sam Wiebe (Canada)

## Aims

1. Education regarding revisions of terms and organization of the epilepsies.
2. Translation of teaching slides/package into other languages.
3. Web resource of Controlled Vocabulary, Videos, EEG, MRI for use in diagnosis and phenotyping in epilepsy.
4. Diagnostic manual for the six most common electroclinical syndromes (BECTS, CAE, JAE, JME, West, LGS).

## Mission

To develop a scientifically-based approach to the classification of the epilepsies to improve diagnosis of epilepsy seizures and syndromes globally.

The Commission on Classification and Terminology has been working hard to refine the new organization of the epilepsies. The previous major changes implemented in 2010 have been updated to modify specific terminology in response to feedback from the epilepsy community and to ensure that it translates readily to other languages. In addition to the well-defined and accepted electroclinical syndromes, the concept of a clinicoradiological entity has been introduced. The major category of etiologically based diagnoses has been expanded to incorporate genetic, structural, metabolic, immune, infectious and unknown. Unclassified epilepsies are also an important subgroup from which new entities will emerge. The Commission and its associated Classification Task Force have worked collaboratively to refine the new terminology and organization.

The Classification Task Force has invested a huge amount of dedication and effort to develop the Diagnostic Manual, the brainchild of Anne Berg. This will be a fabulous online resource defining seizure types and epilepsy syndromes with EEG and video examples. The implementation of the manual has been led by Kate Riney, who has worked with information technology academics at the University of Melbourne to develop this online resource. It has had considerable input from both the Task Force and the Commission. We are sure that this resource will be invaluable to people looking after individuals with epilepsy around the world.

The Status Task Force, led by Eugen Trinka and Daniel Lowenstein, working in collaboration with the Status Task Force of the Epidemiology Commission, has prepared a new classification of status epilepticus. We think this will be a very useful tool for the epilepsy community and will reflect current thinking.

My warmest thanks to all members of the Commission on Classification and Terminology and both task forces for their invaluable input through the term of the Commission.

## New Commission Members (2013-2017)

Sameer Zuberi, Chair (Scotland)  
Ingrid Scheffer (Australia)  
Nerses Bebek (Turkey)  
Robert Fisher (USA)  
Jackie French (USA)  
Edouard Hirsch (France)  
Nobukasu Nakasato (Japan)  
Jukka Peltola (Finland)  
Kate Riney (Australia)  
Eliane Roulet (Switzerland)  
Muhammad Adebayo Salisu (Nigeria)  
Nico Moshé, EC Liaison (USA)

# COMMISSION ON DIAGNOSTIC METHODS



Fernando Cendes

## Commission Members

Chair	Fernando Cendes (Brazil)
Past Chair	William Davis Gaillard (USA)
Secretary	Matthias Koepp (UK)
Translational Research	Ingmar Blümcke (Germany)
Educational Officer	Prasanna Jayakar (USA)
Information Officer	Bruce Hermann (USA)
Treasurer	Friedrich G Woermann (Germany)
Member	Catherine Chiron (France)

## Task Forces

### 1. Neurophysiology:

Chair	Prasanna Jayakar (USA)
Past Chair	Demetrios Velis (Holland)
Secretary	Herman Stefan (Germany)
Members	Francois Dubeau (Canada)
	Eli Mizrahi (USA)
	Aristea Galanopoulou (USA)
	Akio Ikeda (Japan)
	Roberto Caraballo (Argentina)
	Paolo Tinuper (Italy)

### 2. Neuroimaging:

Chair	Matthias Koepp (UK)
Past Chair	William Davis Gaillard (USA)
Secretary	Friedrich G Woermann (Germany)
Members	Catherine Chiron (France)
	William Theodore (USA)
	Donald W Gross (Canada)
	Seung Bong Hong (Korea)
	Dennis Spencer (USA)
	Masako Watanabe (Japan)

### 3. Neuropathology:

Chair	Ingmar Blümcke (Germany)
Secretary	Roberto Spreafico (Italy)
Members	Eleonora Aronica (Holland)
	Hajime Miyata (Japan)
	Andre Palmi (Brazil)
	Maria Thom (UK)
	Harry Vinters (USA)
	Guenther Sperk (Austria)

### 4. Neuropsychology:

Chair	Bruce Hermann (USA)
Secretary	Michael Saling (Australia)
	Maryse Lassonde (Canada)
	Isabelle Jambaqué (France)
	Christoph Helmstaedter (Germany)
	Urvashi Shah (India)
	Ronit Pressler (UK)
	David Loring (USA)

### 5. Focal Cortical Dysplasias:

Chair	Ingmar Blümcke (Germany)
	Eleonora Aronica (Holland)
	Guiliano Avanzini (Italy)
	Scott Baraban (USA)
	Jim Barkovich (USA)
	Albert Becker (Germany)
	Carlos Cepeda (USA)
	Peter Crino (USA)
	Helen Cross (UK)
	Nadia Colombo (Italy)
	Olivier Delalande (France)
	Francois Dubeau (Canada)
	John Duncan (UK)
	Renzo Guerrini (Italy)
	Ajay Gupta (USA)
	William Harkness (UK)
	Philippe Kahane (France)
	Giorgio LoRusso (Italy)
	Joseph Loturco (USA)
	Gary Mathern (USA)
	Imad Najm (USA)
	Cigdem Ozkara (Turkey)
	Andre Palmi (Brazil)
	Charles Raybaud (Canada)
	Alfonso Represa (France)
	Steven Roper (USA)
	Noriko Salamon (USA)
	Andreas Schulze-Bonhage (Germany)
	Roberto Spreafico (Italy)
	Laura Tassi (Italy)
	Maria Thom (UK)
	Annamaria Vezzani (Italy)
	Harry Vinters (USA)

## Aims

The major challenge is the proper evaluation and use of technology and other diagnostic methods to improve care of patients with epilepsy when there is such a broad range of available technology and expertise across the globe. At one extreme is the optimal best practices in developed societies, the other is optimal use of limited resources in underdeveloped economies. These issues touch upon education as well as assessments and utilization of diagnostic methods, and emerging diagnostic methods and disciplines.

### Neuropathology Task Force

The focus of the Neuropathology Task Force was on a new proposal for the classification of focal cortical dysplasias (FCDs) and Hippocampal Sclerosis (HS). The task force on FCD published "The clinicopathologic spectrum of focal cortical dysplasias: a consensus classification proposed by an ad hoc Task Force of the ILAE Diagnostic Methods Commission" (Blümcke et al, *Epilepsia* 2011;52:158-74); and the task force on HS just finished a Consensus Classification of HS that was published recently in "International consensus classification of hippocampal sclerosis in temporal lobe



# COMMISSION ON DIAGNOSTIC METHODS *(continued)*

epilepsy": A Task Force report from the ILAE Commission on Diagnostic Methods. Blümcke et al. *Epilepsia* 2013 doi: 10.1111/epi.12220.

## **Neurophysiology Task Force**

The Neurophysiology Task Force met regularly at regional and international congresses to strategize and follow up various initiatives. One of the primary goals was to integrate efforts with other task forces and commissions to achieve a broader impact. Several of the initiatives have made significant progress and have plans to continue strategic efforts in the next four years. A document with recommendations developed jointly with the Pediatric Epilepsy Surgery Task Force of the ILAE ("Diagnostic Test Utilization in Evaluation for Resective Epilepsy Surgery in Children") is being submitted to the ILAE executive committee for review and a symposium on this topic has been organized at the ILAE meeting in Montreal 2013.

## **Neuroimaging Task Force**

The three main goals of the Neuroimaging Task Force were to (1) formulate "evidence-based" guidelines on "role of imaging in Pediatric Surgery," (2) evaluate the "role of advanced imaging methods in Epilepsy Surgery" and (3) promote global education/training in neuroimaging for neurologists and radiologists. Guidelines for imaging infants and children with recent-onset epilepsy were published in *Epilepsia* in 2009 (50:2147-53), and a commentary on diagnostic testing study guidelines and practice parameters in *Epilepsia* (2011 52:1750-6). During meetings in Boston (AES 2009) and Rome (ILAE 2011), they prepared for a three-day workshop in London, 27-29 September 2012, which comprehensively assessed the clinical role and use of EEG-fMRI, cognitive fMRI for language and memory, as well as the added value of PET and SPECT, and post-processing of MRI. This workshop forms the basis of a "position paper" of expert opinions on the clinical use of these advanced

imaging methods, soon to be submitted to the executive committee of the ILAE for publication in *Epilepsia*. A long-distance neuroimaging teaching program was formally accepted by the ILAE. Members of the imaging task force participated in the annual Neuroimaging web courses offered by VIREPA, which included students from different parts of the world. Some of the students were supported by scholarships offered by ILAE.

## **Neuropsychology Task Force**

The Neuropsychology Task Force organized a special international workshop entitled *Neuropsychology in the Care of People with Epilepsy*. The meeting was held in Toronto, Canada, 3-6 November 2010 and was organized under the auspices of the journal *Epileptic Disorders*. Members from our Neuropsychology Task Force were represented on the organizing and planning committees, served as speakers and discussants, and additionally served as co-editors of the text that emanated from the meeting. The session was attended by 52 specialists from 13 countries representing expertise in adult and pediatric neuropsychology, psychiatry, neurology, neuroimaging, cognitive neurosciences, electrophysiology, and pharmacology.

## **New Commission Members (2013-2017)**

Ingmar Blümcke, Chair (Germany)  
Fernando Cendes (Brazil)  
Andrea Bernasconi (Canada)  
Philippe Kahane (France)  
Callixte Kuete Tegueu (Cameroon)  
Riki Matsumoto (Japan)  
Donald Schomer (USA)  
Sarah Wilson (Australia)  
Sam Wiebe, EC Liaison (Canada)

# COMMISSION ON EDUCATION



Chong Tin Tan

## List of Members

Chair	Chong Tin Tan (Malaysia) Tallie Z Baram (USA) Walter van Emde Boas (Netherlands) Maria Canevini (Italy) Hassan Hosny (Egypt) Angelina Kakooza (Uganda) Ruediger Koehling (Germany) David Labiner (USA) Shih Hui Lim (China) Karupath Radhakrishnan (India) Marcia Elza Yacubian (Brazil)
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## Task Force on Distance Education

Chair	Walter van Emde Boas (Netherlands) Dimitri Velis (Netherlands) Perrine Plouin (France) Jackie French (USA) Holger Lerche (Germany) Catherine Chiron (France) Kuate Callixte (Cameroon) Magda Nunes Verena Hézser-V.Wehrs (Germany) Priscilla Schisler (USA) Li Kuo Tan Chong Tin Tan (Malaysia)
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## Mission and Aims

The role of the Commission on Education is to coordinate the education efforts by the various regional academies and topic-oriented commissions, and to be directly responsible for online educational activities. It also works with non-ILAE partner bodies in joint education efforts.

## Achievements and Challenges (2009-2013)

The roles of the Commission on Education are: (1) Coordinate the education efforts by the various regional academies; and (2) To be directly responsible for online educational activities, educational activities in the IECs, and coordinate education activities of the topic-orientated commissions. The followings are the main achievements during the current term of office (2009-2013), and the challenges for the next commission.

### (1) Educational efforts by the regional commissions

The European, Asian & Oceanian and Latin American commissions continue to have robust educational activities. In particular, summer school is now a regular feature in China and India, as well as Europe and Latin America. Fellowship of 3-12 months' duration is now a regular activity in Latin America as well as Asia and Oceania. There is also a small fellowship program as a joint venture with WFN, involving Mozambique. The ASEPA EEG certification examination is progressing well

and making a significant impact on EEG practice in some of the countries in Asia.

The North American Commission continues with its visiting professorship program to the Caribbean and Latin American countries, and has extended to Africa. The African Commission was formed in 2011 and had their first successful Congress in 2012.

On the other hand, the Eastern Mediterranean region is rather quiet. This will be the challenge for the next commission.

### (2) Online Education and other projects

#### Distance learning courses (VIREPA)

There was a smooth transition for VIREPA, which was under "EUREPA" previously. Since 2009, it has been legally under ILAE, managed by a task force led by Walter van Emde Boas. In 2014 VIREPA will offer courses on EEG, Imaging, Clinical Therapy, Genetics, Sleep, and Psychiatric aspects of epilepsy and new courses are in development. To have regular courses which are in demand, at a cost which is sustainable will be the main challenge for the next commission.

#### Recorded presentations

The decision was made to adopt a low-cost technique to capture the voice and PowerPoint slides in some of the education program and workshops in the IEC and regional congresses, and place it online in the ILAE website. The approach was to let it grow slowly, as there is some reluctance from some of the speakers. It remains a challenge for the next commission to drive its development.

#### Epileptic Disorders

The adoption of *Epileptic Disorders* as ILAE's education journal is an important milestone in the educational effort by the ILAE. It has very good resource materials on their website. It is a challenge for the next commission to integrate the journal with its other activities to facilitate better synergy.

## New Commission Members (2013-2017)

Jaime Carrizosa, Chair (Colombia)  
Chong Tin Tan (Malaysia)  
Alexis Arzimanoglou (France)  
Patricia Braga (Uruguay)  
Lionel Carmant (Canada)  
Amina Gargouri (Tunisia)  
Guenter Kramer (Switzerland)  
Shih Hui Lim (Singapore)  
Daliwonga Magazi (South Africa)  
Hiba Mahmud (Pakistan)  
Walter van Emde Boas (Netherlands)  
Sam Wiebe, EC Liaison (Canada)

# COMMISSION ON EPIDEMIOLOGY



Dale C Hesdorffer



Ettore Beghi

## List of Members

Co-Chair	Dale C Hesdorffer (USA)
Co-Chair	Ettore Beghi (Italy)
Past Chair	Allen Hauser (USA)
Treasurer	Ley Sander (UK)
Secretary	Charles Newton (Kenya)
Educational Officer	Torbjörn Tomson (Sweden)
Information Officer	Giancarlo Logroscino (Italy)
	Ding Ding (China)
Executive Committee Liaison	Marco Medina (Honduras)
	David Thurman (USA)

## Subcommission Members

Mortality Task Force: Giancarlo Logroscino and David Thurman (Co-Chairs), Dale Hesdorffer, Allen Hauser, Ley Sander, Charles Newton and Torbjörn Tomson

Comorbidity Task Force: Dale Hesdorffer (Chair), Ettore Beghi, Roberto Tuchman, Andres Kanner, Michael Trimble, Paola Torelli and Christoph Helmstaedter

Reliability Task Force: Ettore Beghi (Chair), Dale Hesdorffer, Donna Bergen, Allen Hauser, Peter Bergin, Jacqueline French, Marco Medina, Charles Newton, Douglas Nordli and Giuseppe Capovilla

Status Epilepticus Task Force: Shlomo Shinnar (Chair), Additional Epidemiology Commission representative to the joint Task Force: Dale Hesdorffer

## Aims

The Commission on Epidemiology's work is focused on providing standards for the conduct of epidemiological research in epilepsy and for describing the epidemiological evidence on the burden of epilepsy and potential preventive measures.

## Mission

The Commission on Epidemiology's work is focused upon the burden of epilepsy. The work that stems from this focus includes: the development of standards for the conduct of epidemiological research in epilepsy in order to best study the occurrence and burden of epilepsy; the burden of mortality in epilepsy with a specific focus upon potentially preventable causes of death; the spectrum of comorbidity in epilepsy; development of an epidemiological definition of status epilepticus; and assessment of the reliability of epilepsy classifications.

## Commission Activities

The Commission on Epidemiology outlined the task forces, their goals and their membership. Four task forces were created: (1) burden of mortality; (2) comorbidity of epilepsy; (3) reliability and applicability

of testing epilepsy classifications; and (4) definition of status epilepticus for epidemiological studies. The work of the task forces is discussed further in this report.

## Standards For the Conduct of Epidemiological Research

The Commission began its activities by embarking on a document outlining standards for epidemiologic research in epilepsy. This work led to the following manuscript which was published as an *Epilepsia* supplement:

Thurman DJ, Beghi E, Begley CE, Berg AT, Buchhalter JR, Ding D, Hesdorffer DC, Hauser WA, Kazis L, Kobau R, Kroner B, Labiner D, Liow K, Logroscino G, Medina MT, Newton CR, Parko K, Paschal A, Preux PM, Sander JW, Selassie A, Theodore W, Tomson T, Wiebe S; ILAE Commission on Epidemiology. Standards for epidemiological studies and surveillance of epilepsy. *Epilepsia* 2011;52( Suppl 7):2-26. (DOI: 10.1111/j.1528-1167.2011.03121.x)

The Commission oversaw the work in the four task forces. That work is described in the rest of this document.

## Task Force on Burden of Mortality

The objectives of the Mortality Task Force are to: 1. Work on a combined analysis of risk factors for SUDEP; 2. Identify and quantify causes of death in people with epilepsy, including underlying causes/risk factors for epilepsy, and direct consequences of epilepsy or seizures; and to identify risk factors for preventable causes of death in epilepsy; and 3. Identify potential prevention strategies to reduce the burden of mortality in epilepsy.

### Two articles were published on a combined analysis of SUDEP risk factors

Hesdorffer DC, Tomson T, Benn EKT, Sander JW, Nilsson L, Langan Y, Walczak TS, Beghi E, Brodie MJ, Hauser WA for the ILAE Commission on Epidemiology; Subcommission on Mortality. Combined analysis of risk factors for SUDEP. *Epilepsia* 2011;52:1150-1159. | (DOI: 10.1111/j.1528-1167.2010.02952.x)

Hesdorffer DC, Tomson T, Benn EKT, Sander JW, Nilsson L, Langan Y, Walczak TS, Beghi E, Brodie MJ, Hauser WA for the ILAE Commission on Epidemiology; Subcommission on Mortality. Do antiepileptic drugs or generalized tonic-clonic seizure frequency increase SUDEP risk?: A combined analysis. *Epilepsia* 2012;53:249-252.

Parallel Session at the Montreal International Epilepsy Congress, 2013: SUDEP prevention — are we there yet? Chair: E Donner: Talks: SUDEP: Identifying those most at risk, E So; Discussion SUDEP: Does disclosure reduce the risk? L Sander; Epilepsy treatment for SUDEP prevention, T Tomson; Do devices have a role in SUDEP prevention? P Ryvlin

# COMMISSION ON EPIDEMIOLOGY *(continued)*

Evidence-based literature reviews: Two subgroups of the task force are completing systematic, evidence-based literature reviews and analyses on mortality in higher-income countries and on mortality in lower income countries.

## **Task Force on Comorbidity of Epilepsy**

Objective: This task force was convened to develop a systematic review to identify the full scope of epilepsy comorbidities (psychiatric, cognitive, neurological and other somatic). The aim of the results of the systematic review was to: increase awareness of the scope of epilepsy comorbidities through educational symposia at international epilepsy and neurology meetings as well as through dissemination of materials to health departments and health ministries; propose instruments to assess epilepsy comorbidities; and create training materials for clinicians in order to identify comorbidities and understand their impact on epilepsy prognosis and quality of life.

Accomplishments: Questions were developed about the frequency of comorbidities in epilepsy compared to the general population, whether the comorbidity was associated with an increased risk for developing epilepsy, whether epilepsy was associated with an increased risk for developing the comorbidity, whether the comorbidity occurs more in the pre-ictal and post-ictal period than in other periods, and whether the comorbidity in epilepsy is phenomenologically different from the same disorder in the general population.

A literature search has been done, reviewers have selected abstracts, pdfs have been circulated and an abstraction form created. This task force will continue into the new Commission on Epidemiology.

## **Reliability Task Force**

Purpose: To develop a database and use of the database for the assessment of reliability of established and new classifications of the epilepsies. The work was done with repeated interactions with the Commission on Classification.

Accomplishments: Members of the task force were asked to participate in a validation study of different classifications of seizures and epilepsies. The aims and structure of the study focusing on the reliability of four different classifications of the epilepsies (ICD-10, the

forthcoming ICD-11 codes, etiology and seizures) were presented. The ICD-11 classification, commissioned by the WHO, was a modified version of the new ILAE Classification proposal (Berg et al, *Epilepsia* 2010; 51: 576-85). Case reports from different sources were made available for evaluation and information presented in three steps, adding more information in order to consider the situation in low income countries as well as in high income countries. A second reliability study was done during the Latin American Epilepsy Congress in Quito, November 14-17, 2012, using only the ICD-10 and ICD-11 codes. A sample of adult and child neurologists from Latin American countries attending the meeting participated and examined 25 case reports. Manuscripts have been written.

## **Status Epilepticus Task Force**

The aim of this task force was to define status epilepticus for epidemiological studies. The Commission on Classification also developed a task force on status epilepticus. In order to avoid confusion caused by the potential for two reports from the two task forces, the Commission on Epidemiology Task Force on Status Epilepticus merged with the Commission on Classification Task Force on Status Epilepticus to create a unified clinical and epidemiological definition of SE. A manuscript has been written with the contributions of both commissions. The document will be submitted to the Executive.

## **New Commission Members (2013-2017)**

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

# COMMISSION ON GENETICS OF EPILEPSY



Sam Berkovic

## List of Members

Chair	Sam Berkovic (Australia)
Past Chair	Ruth Ottman (USA)
Finance	Shinichi Hirose (Japan)
	Thomas Sander (Germany)
	Peter DeJonghe (Belgium)
Information Officer	Nigel Tan (Singapore)
	Sanjay Sisodia (UK)
	Dan Lowenstein (USA)
Education Secretary	Marcello Kauffman (Argentina)
	Alica Goldman (USA)
	Carla Marini (Italy)
Committee Liaison	Michel Baulac

## Aims

- Initiative 1: Improve the genetic literacy of ILAE members
- Initiative 2: Develop information sources regarding genetics of epilepsy for the public, taking into account regional sensitivities, cultural factors and possible stigmatization related to epilepsy and genetics.
- Initiative 3: Assist in coordination of international efforts to understand the basis of complex epilepsies that will require large multinational cohorts.

## Mission

Improving knowledge and application of genetics in epilepsy across the world.

## Commission Activities from July 2012 through June 2013

- Initiative 1:
- EpiGAD has been regularly maintained, updated and audited.
  - Guidelines on SCN1A testing completed and published in *Epilepsia*.
  - Liaison with GeneTests website continues; draft document underway
- Initiative 2: Pamphlet for general information on epilepsy has been developed
- Initiative 3: The ILAE Consortium on Complex Epilepsies has been established and is functioning well. It has become a useful body for communication between genetics groups, in addition to its direct activities

## Accomplishments (2012-2013)

The major accomplishments have been

- Publication of guidelines for SCN1A testing (Hirose S, Scheffer IE, Marini C, De Jonghe P, Andermann E, Goldman AM, Kauffman M,

Tan NCK, Lowenstein DH, Sisodiya SM, Ottman R, Berkovic SF for the Genetics Commission of the International League Against Epilepsy. SCN1A Testing for Epilepsy: application in clinical practice. *Epilepsia* 2013; 54: 946-52.

- Successful functioning of the ILAE Consortium on Complex Epilepsies. We have accumulated a data set of GWAS data on 10,000 patients with epilepsy from Europe, UK, North America, Hong Kong and Australia. A phenotyping committee has standardized the clinical data, the analysis committee has standardized analytic methods across sites and a meta-analysis is in progress. A meeting to plan the first publication occurred in Montreal (June 2013). Publication anticipated in 2014.

As previously highlighted, the ILAE Consortium previously attracted the attention of NINDS and we were actively involved in planning and executing a successful meeting in San Diego (September 2010) which led to a White Paper on the subject and a Request for Applications from NIH which funded a \$25 million "Center without Walls" on Epilepsy Genetics that is now highly successful.

## Recommendations for Future Work

Increased energy needs to be put into educational aspects of the Commission. The internationalization and large-scale collaboration of genetic research is a priority and the Commission has the reach and authority to be the body to effect this.

## New Commission Members (2013-2017)

Dan Lowenstein, Chair (USA)  
Sam Berkovic (Australia)  
Peter de Jonghe (Belgium)  
Alica Goldman (USA)  
Ingo Helbig (Germany)  
Yuwu Jiang (China)  
Mitsuhiro Kato (Japan)  
Heather Mefford (USA)  
Steve Petrou (Australia)  
Parthasarathy Satishchandra (India)  
Nigel Tan (Singapore)  
Helen Cross, EC Liaison (UK)



# COMMISSION ON NEUROBIOLOGY



Astrid Nehlig



Jeff Noebels

## List of Members

Chair	Astrid Nehlig (France)
Co-Chair	Jeff Noebels (USA)
Past Chair	Annamaria Vezzani (Italy)
Treasurer	Christophe Bernard (France)
Chair of WONOEP	
Commission	Marco De Curtis (Italy)
Liaison to Epidemiology Commission	Edward Dudek (USA) Rafael Gutierrez (Mexico)
Chair of the Education Commission	Uwe Heinemann (Germany) DS Kim (Korea)
Chair of the Translational Task Force	Terry O'Brien (Australia) Filiz Onat (Turkey)
Chair of the Basic Science Task Force	Heidrun Potschka (Germany)
Liaison to Pediatrics Commission	Raman Sankar (USA) Takao Takahashi (Japan)
Liaison to the Therapeutics Commission	Matthew Walker (UK)

## Sub-commissions

### Sub-commission on Education

Uwe Heinemann, Chair (Germany)  
 Guiliano Avanzini (Italy)  
 Esper Cavalheiro (Brazil)  
 Marco De Curtis (Italy)  
 Istvan Mody (USA)  
 Asla Pitkänen (Finland)  
 Liao Weiping (China)

### Sub-commission on Translational Research

Terence O'Brien, Chair (Australia)  
 Greg Holmes (USA)  
 Pete Engel (USA)  
 Aristeia Galanopoulou (USA)  
 Roustem Khazipov (France)  
 Merab Kokaia (Sweden)  
 Holger Lerche (Germany)  
 Matthew Walker (UK)

### Sub-commission on Basic Research

Heidrun Potschka, Chair (Germany)  
 Maria José da Silva Fernandes (Brazil)  
 Alon Friedman (Israel)  
 David Henshall (Ireland)  
 John Huguenard (USA)  
 S Koh (Korea)  
 Filiz Onat (Turkey)

Steven Petrou (Australia)  
 Günther Sperk (Austria)  
 Jana Veliskova (USA)

### Sub-commission for WONOEP

Marco De Curtis, Chair (Italy)  
 Guiliano Avanzini (Italy)  
 Christophe Bernard, Treasurer (France)  
 Pete Engel (USA)  
 Uwe Heinemann (Germany)  
 Raman Sankar (USA)

## Aims

The overall goals of the Neurobiology Commission are (1) to increase the visibility and impact of basic neuroscience research among the epilepsy community, (2) to set up new good laboratory practice for research at the translational level in order to identify new drugs that could reach the level of clinical trials, (3) to bring education to a broader community, (4) to develop specific task forces and (5) spread knowledge during diverse meetings.

## Mission

The mission is the sum of the aims, namely, to provide a forum for neuroscientists involved in epilepsy research to discuss new findings related to the understanding of the basic mechanisms of epilepsy and epileptogenesis in the context of translational research. The Commission will also promote the participation of ILAE Chapters and of young emerging scientists in the field of experimental epileptology. It is also to develop basic science and translational approaches to remaining problems such as establishing better guidelines for preclinical research and with the help of other Chapters and Commissions to develop a better interactive network partly related to specific problems linked to epileptic syndromes more common in less developed countries.

## Commission Goals

The commission has been committed to advancing the recruitment and accelerating the training of younger scientists in the field of basic, preclinical, and translational epilepsy research. Toward that aim, the commission is actively involved in several international educational projects designed to achieve these goals across diverse and emerging areas of biological and preclinical epileptology. These include the following training workshops:

- **2011: WONOEP** at Grottoferata: "Finding a Better Drug for Epilepsy" a three-day advanced workshop involving 77 scientists from academia and industry. Five "Critical Appraisals" covering each of the major themes of the workshop have been published in *Epilepsia* in 2012/2013.
- **2013: WONOEP** in Montreal: "New Technologies to Study the Epileptic Brain" (about 60 scientists

# COMMISSION ON NEUROBIOLOGY *(continued)*

from academia and industry). Several “Critical Appraisals” covering each of the major themes of the workshop are planned to be published in *Epilepsia* in 2014.

- **2011: San Servolo course** on Bridging Clinical and Scientific Research in Epilepsy 2011. An international 14-day residential summer school including young clinical and basic investigators from 55 countries. During this course an innovative research project on neuro-malaria and epilepsy in Africa was identified. This project was led by a young neurologist from Nigeria and was planned to be partly supported by NBC. The application was submitted to the Gates Foundation in 2012 for financial support but was not selected.
- **NBC Symposium at IEC and EEC Congresses**
  - Epilepsy, Dementia/Alzheimer’s Disease and the Temporal Lobe (Rhodes EEC 2010)
  - Metabolic mechanisms of epileptogenesis (Rome IEC 2011)
  - Pediatric epilepsy syndromes: experimental models and therapeutic perspectives (London EEC 2012)
  - Role of non-neuronal cells in epileptogenesis (Montreal IEC 2013)
  - Future: continue organizing NBC symposia at each IEC and EEC, one is currently planned for Stockholm EEC 2014
- **2012: London Translational Workshop** to optimize and accelerate preclinical epilepsy discovery organized by the sub-commission on translational research was held in conjunction with the AES Task Force on Translational Research prior to the EEC meeting in London. Seven task forces were created:
  - o Defining the clinical “gaps to care” and the “opportunities” to develop new treatment approaches for epilepsy
  - o General technical and methodological issues in AET development
  - o Issues related to development of new anti-seizure treatments
  - o Issues related to development of anti-epileptogenic therapies
  - o Issues related to symptomatic and disease modifying treatments affecting comorbidities
  - o Issues related to biomarkers and surrogate endpoints
  - o Issues related to “Stage II pre-clinical trials” and criteria to propose candidates for clinical trials

The proceedings of this workshop gave rise to one paper already published *Epilepsia* and seven additional manuscripts are under review in *Epilepsia*.

- **Gordon Conference**, an international five-day advanced neurobiology of epilepsy workshop on mechanisms of epilepsy and neuronal synchronization taking place in Waterville, USA.
  - o **2010:** “Dynamics, Development and Dysregulation”
  - o **2012:** “Synchronization, Reorganization in the Epileptic Brain”

## Plans for the Future

- Continue organizing the WONOEP meetings at each IEC meeting (2015 and 2017) to gather the best scientists in a given domain of neurobiology to fertilize exchanges and disseminate knowledge.
- A joint project to be launched with the Commission on Education which seeks to advance professional training in epilepsy with a focus on new research projects to solve regional epilepsy issues in less advantaged countries, like the neuro-malaria project in Africa.
- The development of a new course on the Neurobiology of the Epilepsies is planned in Asia for the next future. Associated with this a specific task force will be devoted to the identification of needs which once defined will take specific actions.
- Establish a catalog/list of laboratories and tools of valuable resource to allow training of scientists and clinicians from well-developed countries. This project was not achieved during the present term of the commission for various reasons and will be developed during the next term.
- Neurobiology dissemination at meetings: Organization of basic science symposia in epilepsy meetings but also in less focused meetings (neurobiology, pediatrics, pharmacology).

## New Commission Members (2013-2017)

Marco de Curtis, Chair (Italy)  
Astrid Nehlig (France)  
Jeff Noebels (USA)  
Aristea Galanopoulou (USA)  
Norberto Garcia-Caraisco (Brazil)  
Richard Idro (Uganda)  
Damir Janigro (USA)  
Hoon-Chul Kang (Korea)  
Katja Kobow (Germany)  
Merab Kokaia (Sweden)  
Weiping Liao (China)  
Terence O’Brien (Australia)  
Vicky Whittemore (USA)  
Nico Moshé, EC Liaison (USA)

# COMMISSION ON NEUROPSYCHOBIOLOGY



Andres Kanner



Marco Mula

## List of Members

Co-Chair	Andres Kanner (USA)
Co-Chair	Marco Mula (USA)
	Mike Kerr (UK)
	ES Krishnamoorthy (India)
	Frank Besag (UK)
	Bettina Schmitz (Germany)
	W Curt LaFrance Jr (USA)
	Lilia Nunez Orozco (Mexico)
	Naoto Adachi (Japan)

## Sub-commissions

Task Force on Education:	Co-Chairs A Kanner (USA) and WC LaFrance Jr (USA)
Task Force on Disabling Epilepsy:	Chair ES Krishnamoorthy (India)
Task Force on Child Neuropsychiatry:	Chair F Besag (UK)
Task Force on Psychoses:	Chair N Adachi (Japan)
Task Force on Mood and Anxiety Disorders:	Chair A Kanner (USA)
Task Force on Intellectual Disabilities in Adults with Epilepsy:	Chair M Kerr (UK)
Task Force on Treatment Strategies:	Chair M Mula (Italy)
Task Force on Psychiatric Aspects of Epilepsy Surgery:	Chair A Kanner (USA)
Task Force on Psychogenic Non-Epileptic Seizures:	Chair WC La France Jr (USA)

## Aims

One of the principal aims is to provide clinicians (neurologists and non-neurologists alike) with practical and user-friendly tools to identify the more frequent psychiatric comorbidities in epilepsy and to provide clinicians with a pragmatic approach to the treatment of these psychiatric comorbidities.

## Mission

The mission of the Commission is to ensure that health professionals, patients and their care providers have the educational and scientific resources that are essential in understanding, diagnosing and treating psychiatric and cognitive complications of patients with epilepsy.

## Commission Activities

The Commission continued the project of promoting translation and validation of screening instruments for depression in epilepsy. New versions of the Neurological Disorders Depression Inventory for Epilepsy (NDDI-E) have been validated in several languages and psychometric properties have been

published. The NDDI-E is now available in validated versions for patients with epilepsy in the following languages: English, German, Italian, Spanish, Portuguese, Japanese and Korean. A French version and an Arabic version will be soon available.

The first VIREPA course on psychiatric comorbidities of epilepsies has been developed and recently terminated. The course is structured in two parts. Part one contains basic elements about epidemiology, pathophysiology, clinical aspects and basic treatment approaches of major psychiatric problems in epilepsy, namely mood and anxiety disorders, ADHD. The advanced section discusses more complex problems such as psychogenic non-epileptic seizures and psychoses.

The Commission developed a pragmatic approach for treatment of psychiatric comorbidities in adults with epilepsy. What has been briefly described in the international consensus statement published in *Epilepsia* in 2011 is now fully developed in a special issue of *Epilepsia*, dedicated to this problem. This supplement represents a very practical and user-friendly guide for the pharmacologic and non-pharmacologic treatments of major psychiatric disorders affecting adult patients with epilepsy as well as special populations such as cognitively impaired subjects.

The Task Force on Child Neuropsychiatry is working on a number of consensus documents on specific topics that have been identified as particularly important, namely screening instruments, psychiatric complications of surgery, suicide in adolescents and ADHD in epilepsy.

The Task Force on Therapeutic Strategies published a consensus statement on the FDA alert about suicide during treatment with anti-epileptic drugs.

The Task Force on Intellectual Disabilities developed, in conjunction with the IBE, a web-based survey to explore the views of health professionals involved in the care of patients with intellectual disabilities. Data on burden, mortality/life expectancy, hospitalization and access to care of this subgroup of patients have been collected. Results of this project will be soon available in a special document.

The Task Force on Psychogenic Non-epileptic Seizures developed a specific document on diagnostic standards for PNES. The document will be soon available in *Epilepsia*.

## Accomplishments

- The NDDI-E translated and validated in seven languages
- Consensus statements on AEDs and suicide published in *Epilepsia*
- Diagnostic standards for PNES in press in *Epilepsia*
- Guidance of treatment of psychiatric disorders in

# COMMISSION ON NEUROPSYCHOBIOLOGY *(continued)*

adults with epilepsy published as *Epilepsia* Supplement (8 papers)

- VIREPA course on psychiatric aspects of epilepsy

## **Projects to be finalized by the end of 2013**

- A consensus document on screening instruments for psychiatric disorders in adult patients with epilepsy
- Task Force on Intellectual Disabilities: one document to be finalized
- Task Force on Child Neuropsychiatry: eight documents to be finalized

## **Recommendations for Future Work**

Epilepsy is a complex disorder that needs a comprehensive approach. Psychiatric comorbidities represent an important obstacle complicating the management of patients with epilepsy and significantly affecting their quality of life and prognosis.

Further work is needed to develop models for cost-effective interventions taking into account local specificities. The following aims have been identified as strategic:

- Close link with international psychiatric societies (APA, WPA, WFSBP)
- Identify geographical gaps and local needs
- Develop a consensus document on standard of care for presurgical and post-surgical psychiatric evaluation of patients with epilepsy

## **New Commission Members (renamed Neuropsychiatry) (2013-2017)**

Kousuke Kanemoto, Chair (Japan)  
Marco Mula (Italy)  
Andres Kanner (USA)  
David Dunn (USA)  
Gerardo Filho (Brazil)  
Mike Kerr (UK)  
Robert Kuba (Czech Republic)  
Sung-Pa Park (South Korea)  
Markus Reuber (UK)  
José Francisco Tellez-Zenteno (Canada)  
Tatsuya Tanaka, EC Liaison (Japan)

# COMMISSION ON PEDIATRICS



Doug Nordli



Perrine Plouin

## List of Members

Co-Chair	Doug Nordli (USA)
Co-Chair	Perrine Plouin (France)
	Patrick Van Bogaert (Belgium)
	Helen Cross (UK)
	Kevin Staley (USA)
	Jaime Carrizosa (Columbia)
	Jo Wilmshurst (South Africa)
	Hirokazu Oguni (Japan)
	Dana Craiu (Romania)
	Heung Dong Kim (Korea)
	Roberto Tuchman (USA)
	El Yamani (Saudi Arabia)

## Aims

- To raise awareness about the need to support patients as they transition from pediatric to adult specialty medical care
- To provide written recommendations to ILAE regarding transition to adult health care for pediatric patients with epilepsy.

## Mission

To establish a program that medical centers can incorporate into existing clinical care to assist patients and families with the transition from pediatric to adult medical care.

## Commission Activities 2012-2013

- Autism and Epilepsy (Robert Tuchman)
  - We have increased awareness among the ILAE community regarding the complex relationship between autism spectrum disorders and epilepsy and the importance of identifying and treating social cognitive deficits as part of the comprehensive care of individuals with epilepsy.
  - We have put in motion projects to foster research on autism spectrum disorders and epilepsy.
- Epilepsy Surgery in Children (Helen Cross)
  - A review of the Diagnostic Test Utilization in Evaluation for Resective Epilepsy Surgery in Children has been performed, approved as an ILAE report and submitted for publication in *Epilepsia* with a flow chart of an evaluation protocol for presurgical evaluation

- The Infantile Seizures Task Force is almost completed (Jo Wilmshurst)
  - Data has been collected and analyzed for most areas and analyzing questionnaire from 890 global respondents.
- Transition and Transfer (Jaime Carrizosa, Doug Nordli)
  - Questionnaires were handed out in North and Latin America.
  - Extensive review of literature was done.
  - Revision article was sent to *Epilepsia*.
  - Oncoming work: Build up of pertinent questions. Search of published material to answer these questions. Construction of evidence based guidelines
- E-learning pediatric program (Monka Eisermann, Perrine Plouin)
  - 2nd edition is continuing on course.
- San Servolo Summer School (July 2012)
  - “Management of seizures and epilepsies in neonates and infants” (Federico Vigevano, Perrine Plouin)
  - 63 students from 44 countries; positive evaluation by students

## New Commission Members (2013-2017)

Jo Wilmshurst, Chair (South Africa)  
Perrine Plouin (France)  
Hans Hartmann (Germany)  
Patrick Van Bogaert (Belgium)  
Stephane Auvin (France)  
Amy Brooks-Kayal (USA)  
Petia Dimova (Bulgaria)  
Marilisa Montovani Guerreiro (Brazil)  
Makiko Osawa (Japan)  
Vinayan [K. P.] Puthenivill (India)  
Pauline Samia (Kenya)  
Helen Cross, EC Liaison (UK)



# COMMISSION ON THERAPEUTIC STRATEGIES



Steve Schachter



Bernhard Steinhoff

## List of Members

Co-Chair	Steve Schachter (USA)
Co-Chair	Bernhard Steinhoff (Germany)
Information Officer	Guenter Kramer (Switzerland)
Secretary	Carlos Acevedo (Chile)
Treasurer	Patrick Kwan (Hong Kong)
Education Officer	Jack Pellock (USA)
Past Co-Chair	Jackie French (USA)
Past Co-Chair	Gary Mathern (USA)
Members:	JoAnne Dahl (Sweden)
	Hanneke De Boer (Netherlands)
	Jaideep Kapur (USA)

## List of Sub-commissions and Members

New Strategies of Clinical Therapeutic Studies:  
Jackie French (Chair)

Behavioral Treatments: JoAnne Dahl, Chair

Treatment Gap: Carlos Acevedo, Hanneke De Boer (Chair); Gretchen Birbeck, Tarun Dua, Ley Sander

Surgery: Bernhard Steinhoff (Chair), Mario Alonso, Gary Mathern, Taisuke Oztuki, Cigdem Ozkara, Steven Roper, Felix Rosenow, Americo Sacamoto

Drugs: Guenter Kramer (Chair)

Natural Products: Steve Schachter (Chair), Robert Orynich, Nikolaus Sucher

Pharmacogenomics: Patrick Kwan (Chair), Martin Brodie, Tracy Glauser, Michael Johnson, Terence O'Brien, Nigel Tan

## Aims

To complete efforts begun by the previous Commission and to define and pursue opportunities for progress consistent with the ILAE Strategic Plan in several key therapy-related areas: behavioral treatments, drugs, natural products, new strategies of clinical therapeutic studies, pharmacogenomics, surgery and the treatment gap. A couple of substantial projects were completed. Some of the initiated plans and projects are still ongoing and should be accomplished during the coming years. Some task forces did not report any accomplishments during the past year which will be addressed by the chairs of the Commission.

## Mission

To improve the care of patients with epilepsy by facilitating collaboration among clinicians, scientists, and other professionals in fulfillment of the relevant aspects of the ILAE Strategic Plan.

The therapeutics commission has a broad mandate to review current treatments and to advocate for improvements. Because of the great diversity of the

topics, ranging from the use of natural products to surgery, the Commission created separate task forces. Each task force will focus on a topic of growing interest or pressing importance: natural products, clinical trial strategies, pharmacogenomics and surgery.

## Natural Products Task Force

*Steven Schachter, Chair*

The task force has developed "Epilepsy Naturapedia," a wiki to be launched in 2013 and hosted on the ILAE website, that will be the most comprehensive, current and customizable central research hub for bench-to-bedside scientific information on the use of natural products for the treatment of epilepsy. Among its many features, Epilepsy Naturapedia enables users to search for information using:

1. Common names
2. Scientific names
3. Names of compounds
4. Names of historical neurologists
5. Historical use
6. Pharmaceutical information
7. Published evidence for use in the treatment of epilepsy

Users may apply for privileges to create new pages or edit existing pages by adding links, images, and their own text.

## New Strategies of Clinical Therapeutic Studies Task Force

*Jacqueline French, Chair*

The primary focus of this task force has been global harmonization of regulatory requirements for clinical trials of anti-epileptic therapies. Nine members of EMA and Russell Katz, FDA Neuropharmacology Division Director, attended a task force meeting in Paris on November 17, 2011. Based on the meeting, the task force plans to submit three white papers to the FDA: using add-on therapy for a combined monotherapy/add-on therapy indication, the extrapolation of adult partial onset seizure data to children, and use of the time to event analysis for pivotal trials. Discussions will continue with the EMA.

## Pharmacogenomics Task Force

*Patrick Kwan, Chair*

The task force has outlined a number of issues related to the use of pharmacogenomics to select, titrate and monitor anti-epileptic drug therapies. A critically important step in this effort is to define drug response phenotypes, and the task force is preparing a discussion paper on this topic.

## Surgery Task Force

*Bernhard Steinhoff, Chair*

The surgery task force has conducted a literature review of the surgical treatment of cavernomas

# COMMISSION ON THERAPEUTIC STRATEGIES *(continued)*

associated with epilepsy, outlined recommended surgical approaches and identified opportunities for further research. A manuscript containing the findings and consensus recommendations has been sent for review prior to submission to *Epilepsia*.

Improved and more effective therapies are critically needed and there is no clear breakthrough in sight. It is our hope that our multi-faceted approach will get us to our goal.

## **New Commission Members (2013-2017)**

### **Commission on Medical Therapies**

Patrick Kwan, Chair (Hong Kong)  
Steven Schachter (USA)  
Martin Brodie (UK)  
Alejandro de Marinis (Chile)  
Jacques Doumbé (Cameroon)  
Eric Kossoff (USA)  
Hazel Paragua (Philippines)  
Dong Zhou (China)  
Emilio Perucca, EC Liaison (Italy)

### **Commission on Surgical Therapies**

Bertil Rydenhag, Chair (Sweden)  
Bernhard Steinhoff (Germany)  
Kristina Malmgren (Sweden)  
Mike Sperling (USA)  
Mario Alonso Vanegas (Mexico)  
Sanford Hsu (Taiwan)  
Pavel Krsek (Czech Republic)  
Andrew McEvoy (UK)  
Taisuke Otsuki (Japan)  
Christine Bulteau (France)  
Serge Vulliémoz (Switzerland)  
Tatsuya Tanaka, EC liaison (Japan)



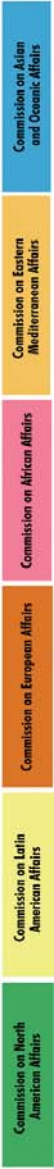
# Chapters

# CHAPTERS

Albania  
Algeria  
Argentina  
Armenia  
Australia  
Austria  
Azerbaijan  
Bangladesh  
Belgium  
Bolivia  
Bosnia Herzegovina  
Brazil  
Bulgaria  
Cameroon  
Canada  
Caribbean\*  
Chile  
China  
Colombia  
Costa Rica  
Croatia  
Cuba  
Cyprus  
Czech Republic  
Democratic Republic of Congo  
Denmark  
Dominican Republic  
Ecuador  
Egypt  
El Salvador  
Emirates  
Estonia  
Finland  
France  
FYR Macedonia  
Georgia  
Germany  
Ghana  
Greece  
Guatemala  
Guinea  
Honduras  
Hong Kong  
Hungary  
India  
Indonesia  
Iraq  
Ireland  
Israel  
Italy  
Ivory Coast  
Japan  
Jordan  
Kazakhstan  
Kenya  
Kyrgyzstan  
Kosovo  
Kuwait  
Latvia

Lebanon  
Lithuania  
Malaysia  
Mali  
Malta  
Mexico  
Moldova  
Mongolia  
Morocco  
Nepal  
New Zealand  
Nicaragua  
Nigeria  
Norway  
Pakistan  
Palestina  
Panama  
Paraguay  
Peru  
Philippines  
Poland  
Portugal  
Qatar  
Romania  
Russia  
Rwanda  
Saudi Arabia  
Senegal  
Serbia and Montenegro  
Singapore  
Slovakia  
Slovenia  
South Africa  
South Korea  
Spain  
Sri Lanka  
Sweden  
Switzerland  
Syria  
Taiwan  
Tanzania  
Thailand  
The Netherlands  
Tunisia  
Turkey  
Uganda  
UK  
Ukraine  
Uruguay  
USA  
Uzbekistan  
Venezuela  
Vietnam  
Zimbabwe

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



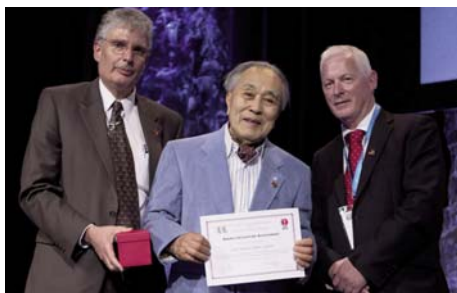




# Other Activities

# AWARDS

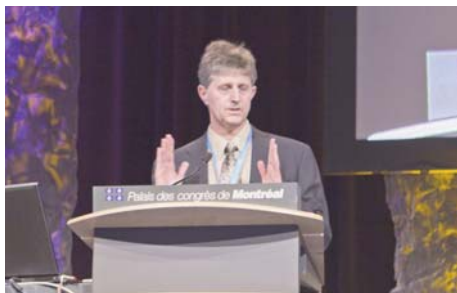
## Lifetime Achievement Award



The Lifetime Achievement Award is given every two years by the Joint Executive Committee of the International Bureau for Epilepsy and the International League Against Epilepsy to honor those truly exceptional persons with a record of achievement in work against epilepsy. It is the highest honor presented by IBE and ILAE, and exceeds even that of those who have been awarded the Ambassador for Epilepsy Award or the Award for Social Accomplishment.

The honoree for 2013 is Juhn Wada, Canada, who received the award during the 30th International Epilepsy Congress in 2013 in Montreal.

## Morris-Coole *Epilepsia* Prize



The Morris-Coole *Epilepsia* Prize is given annually in recognition of an outstanding research paper published in *Epilepsia* the previous year on any field of epilepsy research, either clinical or basic. The prize was initially established through the generosity of Christopher and Sandra Morris-Coole, and is now supported by the ILAE, with the intention of stimulating excellence in epilepsy research as well as rewarding young researchers for outstanding contributions to the field. Award winners receive \$5,000 and an insignia pin, and present the Morris-Coole *Epilepsia* lecture at the Awards Symposium during the International Epilepsy Congress.

The 2013 Morris-Coole *Epilepsia* Prize was awarded to Mark R. Bower of the USA for his paper entitled "Spatiotemporal neuronal correlates of seizure generation in focal epilepsy," *Epilepsia* 2012:807–81.

## Michael Prize



The Michael Prize is an international award for the best scientific and clinical research promoting the further development in epileptology. The prize is awarded biannually to young investigators under the age of 45. The €20,000 award is presented during the International Epilepsy Congress following the election.

The 2013 Michael Prize recipient is Ding Ding of China.

## Social Accomplishment Award



Every two years, the International Bureau for Epilepsy and the International League Against Epilepsy recognize one individual who has carried out outstanding activities aimed at the social benefit of people with epilepsy. Those honored receive a scroll and an award of US \$1,000. The recipient is also invited to attend the International Epilepsy Congress to receive his/her award.

Jane Hanna of England received the 2013 award for her 22 years of advocacy on SUDEP. She also co-founded Epilepsy Bereaved, established to support families, influence clinicians and politicians, and promote research on the causes of epilepsy-related deaths.

# AMBASSADOR AWARDS



Twelve Ambassador for Epilepsy Awards are presented biannually at the International Epilepsy Congress in recognition of outstanding international contributions to activities advancing the cause of epilepsy, either internationally or with international impact. The award consists of an Ambassador for Epilepsy pin and is intended to reflect peer recognition of individual contributions to the international cause of epilepsy. The awards presented at the 30th IEC in Montreal in June 2013 celebrated 45 years of awards.



Gretchen Birbeck  
USA



Alla Guekht  
Russian Federation



Dale Hesdorffer  
USA



Sunao Kaneko  
Japan



Byung-In Lee  
Korea



Li Li Min  
Brazil



Daniel Lowenstein  
USA



Gary Mathern  
USA



Gay Mitchell  
Ireland



Jorge Rodríguez  
USA



Ingrid Scheffer  
Australia



Matthew Walker  
UK

# CONSTITUTION

## Article I — Name

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

## Article II — Effective Date

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

## Article III — Objectives

The objectives of the ILAE are to:

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

## Article IV — Methods

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

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

## Article V — Legal Status

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

## Article VI — Membership

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

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

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

## Article VII — Governance

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

## Article VIII — The Executive Committee

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



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

- j. The Executive Committee shall have the power to formulate at any time Bylaws not in conflict with the Constitution. These Bylaws are legally binding, but a posteriori corrective action may be taken by the General Assembly to revoke or amend these rules.
- k. The Executive Committee shall approve the annual budget of the ILAE and shall set the dues to be paid by the Chapters.

## Article IX — The General Assembly

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

## Article X — Finances

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



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

### **Article XI — Epilepsia**

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

### **Article XII — Commissions and Task Forces**

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

### **Article XIII — International Bureau for Epilepsy**

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

### **Article XIV — Amendments**

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

### **Article XV — Dissolution or Merger**

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

Approved August 2011  
Rome, Italy

# BYLAWS

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.

## I. Elections

1. For each phase of the election, the Elections Commission shall ascertain if candidates are available and willing to serve. Candidates will provide the Elections Commission with appropriate background information on their candidacy. This information will be sent to each Chapter and publicized in the ILAE website.
2. Each Chapter has from 1-6 votes. The number of votes accorded to each Chapter shall depend on the number of professional dues-paying members in that Chapter according to the most recent statement provided by the Chapter. The number of votes shall be determined by a sliding scale as follows:
  - up to 50 members: 1 vote
  - 51 – 150 members: 2 votes
  - 151 – 350 members: 3 votes
  - 351 – 750 members: 4 votes
  - 751 – 1,500 members: 5 votes
  - above 1,500 members: 6 votes

Chapters that do not collect dues shall have one vote.
3. All votes are secret. To ensure secrecy in all voting processes, the Election Committee shall appoint an independent third party, who shall be responsible for receiving the Chapters' votes. The third party will inform Chapters by e-mail or fax within 72 hours that their vote was received, and will transmit the counts of votes to the Election Committee. The number of votes received by each candidate will be disclosed publicly at the completion of each election stage.
4. For the election of the President, the Elections Commission shall submit to the Chapters a list of persons fulfilling the requirements of the Constitution (Article VIII), who are available and willing to serve. The Elections Committee will ask each Chapter to vote for one of them by e-mail or fax. If one of the candidates receives more than fifty percent of all possible weighted votes, this candidate shall be elected. If this is not the case, a run-off shall be held between the two candidates who received the highest number of weighted votes. The candidate in the run-off that receives the highest number of weighted votes cast shall be elected. If both candidates receive the same number of votes, the candidate with the highest number of unweighted votes will prevail. If the tie still holds after counting unweighted votes, the

candidate who had been in the Executive Committee for 8 years already will prevail. In the event that the tie still holds, the older candidate will prevail.

5. Following completion of the Presidential Election, the Elections Commission shall request each Chapter to submit a slate of five names from at least 3 different Regions, without any ranking, as candidates for the remaining officer positions.
6. The geographic representation of the candidates must allow for the eventual election of officers who meet the geographic distribution requirement stated in the Constitution (Article VIII).
7. The Elections Commission shall choose a slate of fifteen candidates on the basis of non-weighted multiple nominations from the lists submitted by the Chapters. The slate must include candidates from at least 3 Regions. The slate may be smaller if less than 15 people are nominated. The Commission shall ascertain that these candidates are available and willing to serve.
8. The Elections Commission shall then submit the slate to each Chapter for voting by e-mail, or fax. In this process, each Chapter shall vote for five candidates from at least 3 different Regions, without any ranking. The final votes for each candidate will be determined by the sum of the weighted votes received from all Chapters. If two or more candidates obtain the same number of weighted votes, the candidate(s) from the ILAE Region(s) with the least representation among the other elected officers will prevail. If a tie persists after consideration of regional representation, the candidate with the highest number of unweighted votes will prevail. If a tie still persists, the oldest candidate(s) will prevail.
9. The President-elect with the advice of the Election Committee will appoint the Secretary-General, Treasurer, and the First Vice President from the newly elected slate.

## 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 Commissions 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 Commissions and Task Forces, submitting such reports for Executive Committee approval and to *Epilepsia*;
    - j) Oversee the publication of the Annual Report;
    - k) Perform such other duties and assume such responsibilities as may be assigned by the President or Executive Committee.
  3. The Treasurer ensures the integrity of the fiscal affairs of ILAE. Specifically, the Treasurer shall:
    - a) Serve as a member of the Executive and Management Committee;
    - b) Ensure that the ILAE accounts are maintained according to international accounting standards, assuring the financial integrity of ILAE;
    - c) Exercise prudence in maintaining the assets of ILAE;
    - d) Report on the financial condition of ILAE at the meeting of the General Assembly and the Executive Committee;
    - e) Submit the financial account of ILAE to an annual audit;
    - f) Working with the staff, develop the annual budget for review and approval by the Finance and Executive Committees;
    - g) Monitor the financial performance of ILAE in relation to the annual budget;
    - h) Ensure the timely payment of all ILAE financial obligations;
    - i) Oversee financial long-range planning;
    - j) Serve as an Ex-Officio ILAE representative in the IBE Executive Committee;
    - k) Retain authority and responsibility for the financial activity of ILAE when such activities are delegated to staff or contracted with an external entity;
    - l) Perform such other duties and assume such responsibilities as may be assigned by the President or Executive Committee.
  4. The Vice President will:
    - a) Serve as a member of the Executive and Management Committee;
    - b) Will assume the responsibilities of the President in his or her absence.
  5. The Immediate Past President assists the President with guidance and advice based upon knowledge of previous Executive Committee policies and past practices. Specifically, the Immediate Past President shall:
    - a) Serve as a member of the Executive and Management Committee;
    - b) Serve as a Chair of the Elections 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).

8. The Editor-in-Chief of *Epilepsia* shall be appointed by the Executive Committee and serves at its discretion, and conducts the day to day editorial business of *Epilepsia*, the official journal of ILAE. It may be appropriate for the Executive Committee to appoint more than one Editor-in-Chief of *Epilepsia*. The editorial content of *Epilepsia* is the responsibility of the Editor(s)-in-Chief. Specifically, the Editor(s)-in-Chief of *Epilepsia* shall:
  - a) Make the final decision on the acceptance or rejection of submitted manuscripts, including reports and documents produced by ILAE Commission and Task Forces and approved by the Executive Committee;
  - b) Make recommendations to the Executive Committee regarding number and role of Associate Editors and Managing Editor;
  - c) Appoint the Associate Editors and the members of the Editorial Board, and supervise communication with the Board;
  - d) Call meetings of the Editorial Board as needed;
  - e) Recommend an annual budget for *Epilepsia* to the Executive Committee;
  - f) Liaise with the publisher and oversee compliance with the contract;
  - g) Assist the Treasurer in supervising expenditures for the *Epilepsia* office;
  - h) Perform other tasks as necessary for the operation of, and maintenance of quality of the Journal.
9. The President, Secretary-General and Treasurer of IBE serve as Ex-Officio, non-voting members of the ILAE Executive Committee. Their function is to facilitate a close and collaborative understanding between IBE and ILAE.

### III. The General Assembly

The General Assembly is convened by the Secretary-General and is chaired by the President. All members of the Executive Committee participate in the meeting of the General Assembly as non-voting members. Unless otherwise indicated, matters brought before the General Assembly shall be decided by majority of weighted vote of those attending an official meeting or responding to a mail ballot.

### IV. *Epilepsia*

1. The Editorial Advisory Board of *Epilepsia* shall consist of all members of the Executive Committee, except for the Editor(s)-in-Chief. It advises the editors on matters of general policies and arbitrates on matters referred to it by the Editor(s)-in-Chief, but shall leave the day to day conduct of the Journal entirely to the Editor-in-Chief and the Editorial Board. The editorial content of *Epilepsia* is

the responsibility of the Editor(s)-in-Chief.

2. The Executive Committee shall approve or terminate any contract with the publisher. It shall determine the budget of *Epilepsia*.
3. The Editor(s)-in-Chief will take all steps necessary to fulfill the aims of ILAE through its journal, *Epilepsia*. The responsibilities of the Editor(s)-in-Chief are described in Article II.7 of the Bylaws.

### V. Resource- and Topic-oriented Commissions and Task Force

1. Each Resource- and Topic-oriented Commission and Task Force shall have a Chair appointed by the President in discussion with the Executive Committee. Each Commission and Task Force shall designate a Secretary, Treasurer, Information Officer, and representative to the Global Outreach activities. If appropriate the Commission should appoint a liaison to the Neurobiology Commission. Liaisons to other Commissions are encouraged. The President will appoint one member of the Executive Committee as the primary contact who serves as an Ex-Officio member.
2. Funds raised by an individual Commission, when not spent within the next fiscal year, may be allocated to the same Commission for the subsequent fiscal year, subject to the Commission providing a plan for the utilization of the funds and approval of the plan by the Executive Committee. At the end of the term of each Commission, any unused funds will be incorporated into the general ILAE assets.
3. The term of office of each Commission shall expire at the end of the term of the Executive Committee, but it may be renewed in the same or a revised composition by the new President of ILAE. It is recommended that the outgoing Chair be retained as a member of the new Commission, if applicable.
4. Task Forces are appointed for specific purposes and their term of office expires when their duties are completed.
5. The Chair of each Commission and Task Force shall make interim reports and recommendations to the Executive Committee as deemed necessary and shall submit a final report at the conclusion of their term. Said final report shall be communicated to the Chapters.

### VI. Chapters' Obligations

1. Chapters shall be open for membership to all professionals working for epilepsy in that country, territory or region as defined in the Constitution.
2. Each Chapter must send to the ILAE Secretary-General the names and contact information of its officers within thirty days after the Chapter's General Assembly Meeting during which a new Executive Committee takes office. If changes in contact addresses occur these must be immediately reported to the Secretary-General of the ILAE.
3. Within thirty days after each Chapter's General Assembly meeting, the Chapter must submit any changes to its Constitution and Bylaws (in English) to the Secretary-General.
4. By March of each year, every Chapter is requested to upload/enter their database, including e-mail addresses, to the ILAE website.

5. Before October 1 of each year, each Chapter shall pay to ILAE annual dues which shall be proportional to the number of dues paying members as of 31 December 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 (US) 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.

## **VII. Fiscal Year**

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

## **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.

## **IX. Meetings**

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

## **X. Regions**

1. Regional Commissions shall consist of:
  - a) representatives elected by the local Chapters comprising the Region (with each Chapter casting one vote) and b) up to two additional members appointed by the President, in consultation with the Executive Committee, among professionals from the Region. The Chair will be elected first, followed by the election of the remaining members. The total number of elected members is five. If more than one candidate receives the same number of votes, the oldest candidate in age will prevail. Each member of the Commission must be a primary member of different Chapters. Appointments to various positions within the Commission are decided by the Commission members based on their rules of procedure. It is recommended that

Regional Commissions have education and information officers, and liaisons to global outreach and to neurobiology. Chapters can belong to only one Region. Special arrangements will be made for Regions with fewer than 6 Chapters.

2. Regional Commissions should meet from one to three times a year and must submit an annual budget for approval to the Executive Committee.
3. Regional Commissions should aim to develop, stimulate and coordinate the epileptology agenda in their part of the world.
4. Regional Commissions should promote the activities of local Chapters, encourage similar policies and administrative structures and facilitate their involvement within the global ILAE agenda.
5. Regional Commissions can have designated funds which they access via the budget process.
6. Regional Commissions should coordinate local educational activities.
7. Regional Commissions should run their Congresses under the direction of the International Director of Meetings.
8. Regional Commissions should review epilepsy services and the size of the treatment gap in each country and aim to improve the former and reduce the latter.
9. Regional Commissions should develop documents with the aim of stimulating local medicopolitical initiatives and improving patient care.

## **XI. Cooperation with the International Bureau for Epilepsy (IBE)**

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



8. A quorum for a JEC shall be the presence of a majority of the members of each of the ILAE and IBE Executive Committees.
9. A JEC may be convened at any time mutually acceptable to the Presidents of both the ILAE and IBE.
10. To be considered by a JEC, a motion must be moved by a member of one Executive Committee, and seconded by a member of the other.
11. Responsibility for administration, minuting, etc. of JECs shall be shared equally between the Secretaries-General of the ILAE and IBE, in a manner acceptable to both.
12. Responsibility for overseeing all financial matters considered by JECs shall be shared equally between the Treasurers of the ILAE and IBE, in a manner acceptable to both.
13. A Joint Committee, consisting of the voting members of the ILAE Executive Committees and the Management Committee of IBE, is authorized to take actions in the name of a JEC between JEC meetings. Such actions must:
  - a) Be approved by a majority of each of the Committees of the ILAE and IBE;
  - b) Be in accord with policies of both the ILAE and IBE;
  - c) Involve neither Executive Committee in expenditure exceeding a sum to be set by each Executive Committee;
  - d) Be notified to each Executive Committee as soon as possible;
  - e) Be ratified by each Executive Committee at its next meeting.

## **XII. Indemnification**

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

## **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.

Ratified October 2011. Amended June 2012, June 2013.