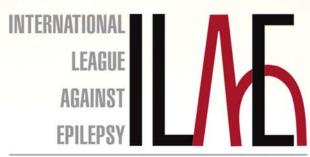
Stand Up for Epilepsy – Speaking With One Voice



Established 1909



INTERNATIONAL LEAGUE AGAINST EPILEPSY 2012 ANNUAL REPORT

OUR VISION

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

OUR MISSION

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

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PRESIDENT'S REPORT



It is with great pride that I write this for the 2012 Annual Report of the International League Against Epilepsy (ILAE). Our Chapters and our Executive Committee have strived to fulfill the goals of the Strategic Plan and to prepare for the transition to the new Executive. The first phase of the elections has been completed (see the report by Peter Wolf, Chair of the Election Committee). We all congratulate President-Elect Emilio Perucca and the newly elected members of the Management Committee: Tatsuya Tanaka, First Vice President; Sam Wiebe, Treasurer and Helen Cross, Secretary-General.

The first goal of the Strategic Plan states: **ILAE shall** serve all health professions as the premier international resource for current and emerging knowledge on epilepsy prevention, diagnosis, treatment, and research.

We held four Regional Congresses this year, each with an impressive program. These include the 9th Asian-Oceanian Epilepsy Congress in Manila (21-25 March 2012); the African Epilepsy Congress in Nairobi (21-23 June 2012); the 10th European Congress of Epileptology in London (30 September-4 October 2012); and the Latin American Epilepsy Congress in Quito (14-17 November 2012). In conjunction with 66th American Epilepsy Society Annual Meeting in San Diego, California, USA (November 30-December 4, 2012) the 4th Biennial North American Congress was held. Notably, the Nairobi Congress was the first African Congress organized jointly by the ILAE and the International Bureau for Epilepsy (IBE) and is a major component of the educational activities targeted to the African continent by our newly formed Commission on African Affairs. Next year we will have our 30th International Epilepsy Congress in Montreal, Quebec, Canada, 23-27 June 2013. I would like to take this opportunity to congratulate the organizers of the Congresses on an outstanding job in the delivery of state of the art educational programs and disseminating research findings. A distinguished feature is the presentation of regional awards as well as the recognition of several of our Chapters with more than 50 years of service to people with epilepsy.

The following awards were presented at the 10th European Congress on Epilepsy in London, UK. Photos and more information can be found on page 112.

- Recognition for **100 years of service**: ILAE Chapter of Great Britain
- Recognition for **75 years of service**: Dutch League Against Epilepsy
- Recognition for 50 years of service: Israeli Chapter; Italian League; Swiss League Against Epilepsy, and French League.

The following Chapters were recognized for 50 years of service at the 7th Latin American Congress on Epilepsy in Quito, Ecuador.

- Argentinean League Against Epilepsy
- Brazilian League Against Epilepsy
- Chilean League Against Epilepsy
- Cuban League Against Epilepsy
- Peruvian League Against Epilepsy
- Uruguayan League Against Epilepsy.

The League solidified the organizational and financial stability of its long distance education program by acquiring direct control and investing in the expansion of the Virtual Epilepsy Academy (VIREPA) and by creating a Task Force on Distance Education led by Walter van Emde Boas within the Education Commission. The Task Force is organizing and conducting the various teaching courses with the Regional Academies and Topic-Oriented Commissions. In order to increase the attractiveness and accessibility, ongoing courses have been shortened and either divided into basic and advanced parts (Imaging and Pharmacotherapy) or split in a general course (EEG) to which now a totally new course on Pediatric EEG and Epilepsy has been added. The course on Genetics is being remodeled along the same lines. For 2012-2013 new courses on Psychiatric Aspects and Sleep and Epilepsy are in development. Preliminary discussion has been taken to organize a course for primary caregivers in Sub-Saharan África in collaboration with the Task Force on Seizures and Epilepsy in the Tropics and with the African Commission.

We have also firmed our collaborations with the World Federation of Neurology (WFN), International Brain Research Organization (IBRO) and the International Child Neurology Association (ICNA) so that we can work together toward our common goals by sharing resources and, of course, the enthusiasm of our volunteers.

Another activity is the Joint ILAE/AES workshop (with the generous co-sponsorship by CURE, Epilepsy Therapy Project, and Autism Speaks) to optimize preclinical epilepsy therapy discovery. A detailed report can be found on page 26.

The second goal of the Strategic Plan states: **The ILAE** shall serve as an international information resource and leader for optimal, comprehensive epilepsy care.

Our collaborations with WHO and IBE under the aegis of the Global Campaign and the Global Outreach Task Force are entering a new phase promoting the

PRESIDENT'S REPORT (continued)

sustainability of ongoing efforts to optimize care and improve health policies in a country-specific manner. Examples include the worldwide effort to specifically designate epilepsy as a disease in the WHO Mental Health Gap (mhGAP) Action Plan, update the WHO list of essential antiepileptic medications; enhance access to interventions; and work with WHO to map research priorities, provide effective training courses for non-epileptologists and modify local current delivery of care paradigms. We would like to thank Dr Shekhar Saxena, Director, and Dr Tarun Duat, Medical Officer, of the Department of Mental Health and Substance Abuse, World Health Organization, for their efforts in these initiatives and their continuous commitment to change the lives of people with epilepsy for the better (http://www.who.int/mental health/mhgap/en/). Finally, we have collaborated with WHO in the newly published Guidelines for Neonatal Seizures. The guidelines may be accessed at http://www.who.int/iris/bitstream/10665/77756/1/ 9789241548304 eng.pdf.

In this report we have included documents and related progress achieved by regional initiatives, including the IOM report (page 24), the PAHO agreement (page 39) and JTF efforts (page 28).

There are also two new country specific achievements: The Korean Chapter completed the project of Epilepsy Renaming whereby epilepsy got a new, more neutral, Korean name as an effective way to challenge the negative attitude toward epilepsy in Korea. A milestone was marked in the history of the Philippine League

Stand Up For Epilepsy EARL LAS

Against Epilepsy when a partnership between the Department of Health was solidified with the signing of the Memorandum of Understanding recognizing epilepsy as one of the mental health disorders that will be given priority in terms of programs and legislation by the Department of Health.

Details can be found in the 2011 Summer Epigraph. http://www.ilae.org/Visitors/Centre/VIREPA.cfm

The Task Force on Sports and Epilepsy launched the photographs of famous sports persons meeting people with epilepsy. The photographs convey the message that people with epilepsy, like athletes themselves, can be inspired to achieve their goals and lead full and active lives. The collection is intended for publication as a book of photographs, and the images will be made available to National Chapters for advocacy initiatives in their own countries. Details can be found on page 25.

Purple Day, which emphasizes epilepsy awareness, is March 26th. It started with a presentation on epilepsy to a third grade class in Nova Scotia and has grown to a global campaign drawing awareness for epilepsy to more than 60 countries around the world thanks to the partnership of the Anita Kaufmann Foundation and the Epilepsy Association of Nova Scotia. To learn more about Cassidy and Purple Day go to www.purpleday.org.

The third goal of the Strategic Plan states: The ILAE shall work to ensure its ongoing organizational and financial viability.

ILAE's organizational viability is strong. At last count, 109 National Chapters are members of the ILAE, and we have had the pleasure of welcoming seven new Chapters recently. Applications from 23 additional countries are at various stages of maturity. This includes a new Caribbean Chapter composed of several countries, a development which was made possible by the most recent amendment to the ILAE Constitution. This allows the consolidation of several countries from one geographic area or territory into a single Chapter. By being active participants within their Regional Commissions, individual Chapters can benefit from the educational, legislative and healthcare resources that are developed within the ILAE Regional Commissions. For more on ILAE Chapter benefits, see the Secretary-General's report on page 9.

The League can be proud of its financial viability. Thanks to the efforts of our Treasurer we have been able to streamline the ILAE administrative structure and review its financial operational practice to ensure an efficient and effective management. Details on these accomplishments can be found in the Treasurer's report, beginning on page 6.

PRESIDENT'S REPORT (continued)

The ILAE Congress Staff managed five Congresses during the period July 2011 to November 2012. During that time, 10,004 attended the Congresses from over 110 countries worldwide, with 877 speakers and Chairs. A total of 240 people were assisted to attend these Congresses by means of bursaries awarded. For more detailed information on all ILAE Congresses, see page 18.

The ILAE Congress Staff is also currently working on arrangements for the 31st IEC in 2015, as well as the Regional Congresses taking place in 2014, 2015 and 2016.

This past year, Peter J Berry, CAE, Chief Staff Officer for the League for the past 15 years, decided he was ready to step back from his management responsibilities, yet continue to work on specific League projects with the new title of Advisor. Priscilla Shisler, MEd, who has worked beside Peter and supported the Executive Committee and the Commissions for the last two years, assumed the title of Administrative Director. More information about ILAE Staff can be found on page 10.

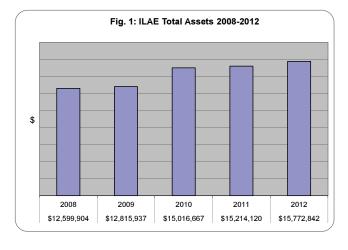
Solomon L Moshé President

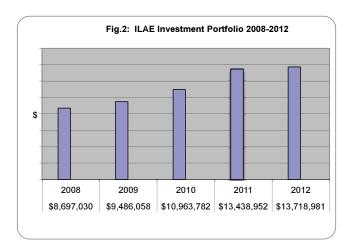
TREASURER'S REPORT



As I am writing this report in the final year of my term as ILAE Treasurer, it is appropriate for me to take a look back and assess how the financial governance of the League has fared in the last four years. My mandate from the Strategic Plan was to "streamline the ILAE administrative structure and review its financial operational practice to ensure an efficient and effective management." Through gratifying teamwork with our Executive Committee, Finance Committee and our staff at Association Resources (AR), a number of actions have been accomplished to meet these goals:

- Administrative expenses were reduced by about one-third early in the term through a reorganization of our
 operations. This involved, among other actions, closing the office in Brussels and transferring those activities to
 the IDM (International Directorate of Meetings) office in Dublin. These activities related to Chapter
 communication are coordinated by Gus Egan.
- In 2009 a new five-year contract for the publication of *Epilepsia* was negotiated with Wiley-Blackwell; this contract guarantees annual increases in revenue for the League over the period 2011-2015. Along the same lines, ILAE and IBE jointly negotiated a new five-year contract with Chancel and our International Directorate of Meetings, regulating the Congresses' financial arrangements for the years 2010-2014. Finally, in 2011 we reorganized the administrative structure of VIREPA (Virtual Epilepsy Academy) by finalizing a renewable three-year contract that will ensure the optimal expansion and coordination of our long-distance educational activities well into the next term.
- To improve transparency and ensure optimal allocation of our resources, in 2009 we introduced a new procedure for evaluating the annual budget requests made by our Commissions and Task Forces. At the end of each year Commissions and Task Forces submit budget applications using a standardized form which includes a report on funds already spent, a description of ongoing and new projects, a list of foreseen expenditures for which support is requested, and a time scale of the projects. The applications are first reviewed by an external Budget Review Task Force, which includes mostly members of the Strategic Plan Committee and operates in liaison with the Chair and Treasurer of each Commission and Task Force. The assessments and recommendations made by the Task Force are forwarded to the Finance Committee, and ultimately to the ILAE Executive for final review and deliberation. This procedure has worked well and provides, in my view, a useful mechanism to ensure a transparent accounting of our activities and an unbiased allocation of funds to Commissions and Task Forces.
- To ensure that adequate resources are maintained for the League's future activities, it is essential to guarantee the preservation of an optimal level of financial reserves, the construction of a carefully balanced investment policy, and the appropriate supervision and oversight of our investments. To this end, we created a Finance Advisory Subcommittee consisting of volunteer professionals from the international corporate and banking world with top level expertise in financial matters. The assistance of our advisors has been extremely helpful in improving the quality of our financial governance. In particular, I wish to acknowledge their excellent contribution to the revision of our Investment Policy and to the creation of a carefully structured Cash Management Policy. Our advisors have also been invaluable in supervising the activities of our investment firm, in guiding the selection of a new firm when this was deemed to be appropriate, and in steering the diversification of our investment portfolio in times made difficult by the high volatility of financial markets and the unfolding of the sovereign debt crisis.





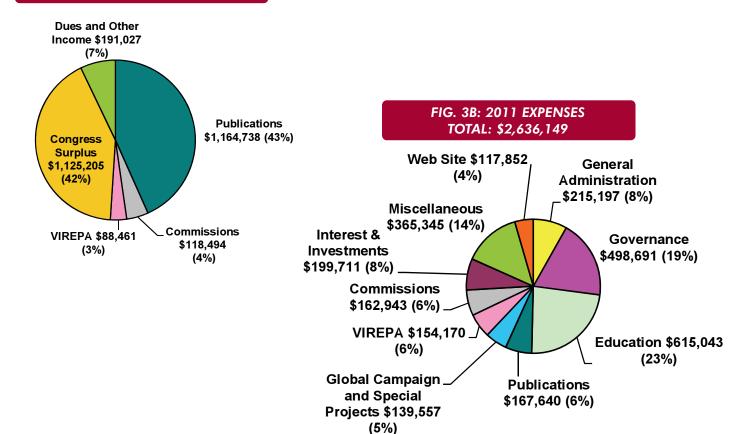
TREASURER'S REPORT (continued)

Thanks to a large extent to the achievements listed above, I am pleased to report that, despite the troubles which affected the financial world in recent years, the League's finances are in a healthy state and well placed to meet our challenges for the years to come. Specifically, our total assets have increased 25 percent from \$12,599,904 on December 31, 2008 to \$15,772,842 (non-audited estimate) on July 31, 2012 (Figure 1). Our investment portfolio has increased over 50 percent in the same period from \$8,697,030 to \$13,718,981 (Figure 2). These positive results are particularly important when we consider that in future years the League's revenue could be adversely affected by at least two factors: (i) the open access publishing policy, which may impact the profitability of our journal, and (ii) changes in the regulatory and financial climates leading to decreased support of the pharmaceutical industry to our international Congresses which represent a significant source of income for the League. Being aware of these threats, the Executive Committee has set the ambitious goal of building up our reserves to a level close to \$20 million by the year 2018. If we achieve this target, we should be able to generate sufficient returns from investments to allow us to sustain our activities without having to draw steadily on our reserves.

Another positive consideration is that the League has increased its reserves without curtailing in any way financial support of its activities. In actuality, activities have been enhanced in many ways, as detailed in the President's report. Income and expenditures for 2011 are summarized in Figures 3A and B. As in the past, surpluses from Congresses and revenue from publications accounted for over 80 percent of our income while expenses became increasingly diversified. Educational activities represent the highest expenditure, with 6 percent invested in VIREPA (Distance Education) and 23 percent in the Commissions' educational activities. An explanation about the investment expense illustrated in Figure 3B:

Acting upon advice from our financial advisors and in accordance with the new Investment Policy, investments were sold in the Fall of 2011 and replaced with new investments recommended by our new investment consultants. This resulted in an accounting loss of approximately \$200,000; however, the market value of our investments actually increased 23 percent in 2011.

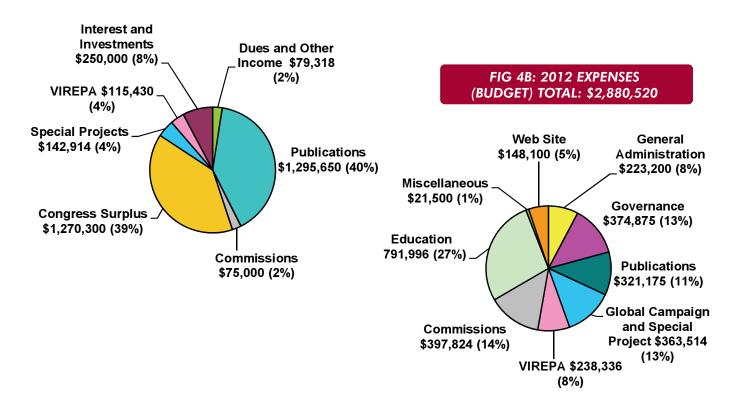
FIG. 3A: 2011 REVENUE TOTAL: \$2,687,925



TREASURER'S REPORT (continued)

Compared with 2011, the 2012 budget forecasts an increase in expenditure by about \$250,000, and an overall positive balance of over \$300,000 (Figure 4A and B) which, hopefully, will result in a further increase in our reserves, in accordance with the goals of the Strategic Plan. Although 2013 is a transitional year with new teams coming on board at the Montreal Congress in June, existing Commissions and Task Forces have been notified that they will be able to work at full speed for the entire fiscal year, aiming at completing their projects by December 2013. Special provisions for that are being made in the budgeting process for 2013, which has recently been set into motion.

FIG 4A: 2012 REVENUE (BUDGET) TOTAL: \$3,228,612



Since this is the last report that I am writing in my capacity as Treasurer, it is my duty on this occasion to express my gratitude to the many people without whose help and support none of the above achievements could have been accomplished. These include our excellent Financial Manager, Donna Cunard, and all members of the Executive Committee, the Finance Committee, the Finance Advisory Subcommittee, and the Budget Review Committee. Additionally, I wish to thank the other members of the AR team, Peter Berry, Priscilla Shisler and Cheryl-Ann Tubby, as well as Eve Bolger and Maria McDonnell who are in charge of finances at the Chancel Office in Dublin. Finally, a warm welcome to Sam Wiebe, who will take up his new position as the next Treasurer of the League in June 2013. Having worked closely with Sam for the past four years, I am impressed by his energy and capabilities, and I am sure that the League's finances in the next term will be in very good hands.

Emilio Perucca ILAE Treasurer

SECRETARY-GENERAL'S REPORT



Because the ILAE is an organization of National Chapters, one of the most gratifying developments in the organization is the birth of new Chapters and their successful incorporation into the ILAE family. At last count, 109 National Chapters are members of the ILAE, and we have had the pleasure of welcoming seven new Chapters: Bolivia Cameroon, El Salvador, Kosovo, Kuwait, Nigeria and Sri Lanka. Applications from 23 additional countries are at various stages of maturity. This includes a new Caribbean Chapter composed of several countries, a development which was made possible by the most recent amendment to the ILAE Constitution. This allows the consolidation of several countries from one geographic area or territory into a single Chapter.

What does the ILAE provide to its Member Chapters? These are some of the benefits:

At the most basic level, the largest benefit is obtaining official status as the national professional epilepsy organization. There can be only one ILAE Chapter in each country (or group of countries in a territory); therefore, being officially designated as the ILAE Chapter provides the national organization with the formal jurisdiction to approach governments, organizations and individuals in such an important capacity.

Chapters in good standing have the right to vote in the election of the ILAE leadership, as well as in important decisions brought to vote during the general assembly of Chapters. Being an ILAE Chapter means having a voice in the international epilepsy community.

Chapters from resource poor countries have access to discounted or no-cost access to *Epilepsia*, the official journal of the ILAE. For more information on eligibility and no-cost access, contact gus@epilepsycongress.org, or visit HINARI.

The ILAE provides Chapter members bursaries for Congresses, workshops, fellowships and other educational activities.

By being active participants within their Regional Commissions, individual Chapters can benefit from the educational, legislative and healthcare resources that are developed within the ILAE Regional Commissions.

One of the most important mandates of the ILAE is education of professionals providing care to people with epilepsy around the world. Increasingly, support from the ILAE for educational activities at all levels (e.g. primary healthcare, secondary and tertiary care) is being coordinated through ILAE specific Commissions, and in many cases through its six Regional Commissions (i.e., Africa, Asia & Oceania, Eastern Mediterranean, Europe, North America, Latin America).

The ILAE Commissions receive funds through a standardized budget review process every year, to help organize and implement such educational activities, many of which are specific to the countries and Chapters within that Region. It cannot be overemphasized how important it is for individual Chapters to participate actively in their regional activities, not only to gain access to the existing educational resources, but also to determine where resources should be allocated to be most effective. We need everyone's input to achieve our goals.

Examples of educational activities available to Chapter members can be found here on the ILAE official website, and under the microsite for each of the world Regions (for example, Latin America).

An important development of regional activities from which individual Chapters can benefit is the Regional Epilepsy Congress, held every two years in each Region. These Congresses afford Chapter members the opportunity of educational and academic enrichment that is not only very high quality, but also highly relevant to their geographic and cultural context. The Regional Congresses have gained increasing success and popularity, as attested by the most Regional Congresses held in 2012: November 2012 in Quito, Ecuador (7th Latin American Congress on Epilepsy), September 2012 in London, England (10th European Congress on Epileptology), March 2012 in Manila, Philippines (9th Asia and Oceania Epilepsy Congress), June 2012 in Nairobi, Kenya (1st African Epilepsy Congress), and December 2012, San Diego, USA (4th North American Regional Epilepsy Congress during the American Epilepsy Society Annual Meeting).

Samuel Wiebe Secretary-General

STAFF REPORT



This past year, Peter J Berry, CAE, Chief Staff Officer for the League for the past 15 years, decided he was ready to step back from his management responsibilities. He requested that he work on specific League projects as determined by the



Management Committee. The leadership approved this change and Peter's new title is Advisor.

I was very pleased that the Management Committee designated me to assume Peter's responsibilities and changed my title from Leadership Liaison to Administrative Director. As Director, I support the Management and Executive Committees, the Commissions, the VIREPA distance learning program and the website team. I look forward to increased opportunities to interact with the members of the ILAE via e-mail and at international and Regional Congresses. I feel fortunate to be able to continue to work with Peter Berry in his new role. He has contributed much to the ILAE and we look forward to his continued involvement.

The ILAE staff is privileged to have interesting and rewarding work to do in support of the League's Mission and Strategic Plan. As you have read in this Annual Report, there are many important initiatives and activities that have taken place around the world over the past year. Below are some of the ways the staff has supported their implementation.

- Played a key role in coordinating the election process and communicating with the Chapters, under the direction of the Elections Commission
- Organized a series of poster displays at the Regional Congresses to give Chapters the opportunity to inform each other about their accomplishments
- Assisted the Secretary-General with almost two dozen applications for Chapter status in five different Regions
- Facilitated communication between Chapter Officers, League Officers and staff by organizing and staffing the Chapter Conventions at four Regional Congresses in Manila, Nairobi, London and Quito
- Continued to enhance the look and functionality of the website in collaboration with Jean Gotman, Director of Interactive Media; added graphics and photos along with an increased number of video sessions from Regional and International Congresses; established an ILAE presence on Facebook and Twitter to push out news about important League news and initiatives; significantly improved search funtionality
- Strengthened our outreach to the Commissions by seeking updates and news for inclusion on the main website, as well as Commission-specific websites; populated the Member pages of the Commission sites with Commission and Task Force names and photos

- Assisted Commission Chairs in setting up planning meetings at the 4th Biennial North American Congress in San Diego, CA
- Supported the Treasurer, the Commission Chairs and the Budget Task Force in the development of the 2013 budget
- Provided increased coordination and moderation for an expanded VIREPA distance education program, which now offers seven courses
- Compiled a repository of Health Ministers in each country where the ILAE has a Chapter to assist with lobbying governments to improve services, resources and care for people with epilepsy
- Nurtured relationships and developed new ones with Chapter members by staffing the ILAE booth at five Regional Congresses in Manila, Nairobi, London, Quito and San Diego.

I would like to express appreciation to the amazing ILAE staff team for their hard work on behalf of the League this past year — Donna Cunard, Gus Egan, Carla Glynn, Verena Hézser-v:Wehrs, Mary Anne Lynch, Deborah Flower, Steve Shane and Cheryl-Ann Tubby.

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 and Carla Glynn are based in the Dublin, Ireland, IDM Office. They work primarily with the League's Chapters, coordinate the Chapter





Conventions, maintain the Chapter database, liaise with the Secretary-General on the processing of new Chapter applications and promote the League through the use of the booth.

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 administrates, moderates and evaluates the VIREPA



program. Verena also collaborates with the development of new courses and course formats.

Mary Anne Lynch has joined the ILAE staff to provide additional support for the growing VIREPA distance education program. She will work beside Verena and Priscilla to administer, moderate and evaluate several of the VIREPA courses.

STAFF REPORT (continued)

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.



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.



And last but not least, our sincere thanks to Cheryl-Ann Tubby for her efforts over the years as the primary contact for the League's Information Officer and in coordinating the production and distribution of *Epigraph* and the Annual Report.

We look forward to the coming year and to assisting the ILAE's Executive Committee, Commissions, and Chapters with the development and implementation of the League's programs and services.

Priscilla Shisler, MEd Administrative Director

FIRST VICE PRESIDENT'S REPORT



Achievable Project: Last 12 Months of the Term

The new ILAE Constitution was ratified by the General Assembly at the 29th International Epilepsy Congress held in Rome on 31 August 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 by frequent meetings of the Constitution Task Force and Executive Committee members, according to the amended Constitution. Thus, Amended Bylaws were ratified by the Executive Committee on 2 October 2011. The amended Bylaws were assured that they were aligned with the approved Constitution. 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) for their devoted efforts in order to accomplish these difficult tasks during the past three years.

(1) Retrospective verification of the amended Constitution

It is important to verify whether the amendment of the Constitution and Bylaws is well adapted to the League, in the practical use. The League has been electing its new President and Executive Committee Officers for 2013-2017. The Constitution Task Force paid particular attention in order to detect any remaining inconsistencies or ambiguities.

(2) Retrospective verification of the amended Bylaws

The International League Against Epilepsy (ILAE) has achieved worldwide success over the first century of its existence. This success is reflected by the growth of regional activities and collaboration among different Regions (Asia/Oceania, Europe, North America, Latin America, Eastern Mediterranean and Africa). To better represent its constituency, 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.

For the next ILAE election (2013-2017 term), the Constitution Task Force has been carefully checking and verifying the amended Bylaws. The president and members of the Management Committee were elected successfully according to the process of new Constitution and Bylaws. However, particular care and attention should be taken to the election of the Regional Chair of the Regional Commission (Executive Committee Member by the new Constitution), because the structures and history of each ILAE Region are very different. Further discussions with the Election Commission and Executive Committee will be necessary in order to resolve these important issues for the consistency and transparency of the Regional Chair Election.

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 and Oceanian Affair, many collaborative works were performed during the past 12 months. In particular, the 9th Asian and Oceanian Epilepsy Congress (AOEC) in Manila 2012 was a great success. The next AOEC will be held in Singapore in 2014. The Scientific Organizing Committee has already started its activities.

Tatsuya Tanaka First Vice President

EPILEPSIA REPORT





Epilepsia had another successful year. Volume 52 (2011) comprised 2,366 pages, which included twelve regular monthly issues and also the following eight supplements:

- S1 Beyond Seizures: Mechanisms Underlying Epilepsy Spectrum Disorder – Frances E Jensen, guest editor
- S2 Severe Myoclonic Epilepsy Dravet Syndrome: Thirty Years Later – Renzo Guerrini, Michelle Bureau, Bernardo Dalla Bernardino, and Charlotte Dravet, quest editors
- S3 Immunity and Inflammation In Epilepsy: Mechanistic Insights and Therapeutic Perspectives – Annamaria Vezzani and Stephan Rüegg, guest editors
- S4 Advanced Neuroimaging In New-Onset Epilepsy Bernd Pohlmann-Eden and Michael Esser, guest editors
- S5 Long-Term Outlook of Lennox-Gastaut Syndrome and Related Epilepsies: Care for a Lifetime – Laurie Douglass, guest editor
- S6 Abstracts from the 29th International Epilepsy Congress (online only)
- S7 Standards for Epidemiological Studies and Surveillance of Epilepsy – David Thurman et al, guest editors
- S8 Proceedings of the 3rd London-Innsbruck Colloquium on Acute Seizures and Status Epilepticus – Simon Shorvon and Eugen Trinka, guest editors

During the 2011 journal year, *Epilepsia* received over 1,000 submissions and accepted 32 percent of peerreviewed manuscripts. The accepted/published manuscripts can be categorized as follows: 19 reviews (including historical reviews); 233 full-length original research reports, four special reports (primarily ILAE Commission reports); 62 brief communications; 32 Gray Matter material (not peer-reviewed, including letters, commentary, workshop reports, and various communications). The editors balance the inclusion of papers likely to be highly cited (thus raising the Impact Factor) with an equally important goal of serving the epilepsy research community by publishing a range of interesting reports (including those that are not likely to be highly cited).

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 653 institutional subscriptions to *Epilepsia* (a slight decline from 2010), 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 2011 there were over 1,100,000 full-text downloads from *Epilepsia*, reflecting a significant increase over the previous year. In bibliometric terms, in 2010 *Epilepsia* was ranked 31st of 191 journals in the clinical neurology category, had an Impact Factor of 3.96 and an EigenFactor of 0.03 (both little-changed from 2009). The *Epilepsia* Impact Factor was significantly higher than that of any of the other epilepsy sub-specialty journals.

Wiley introduced a smart phone app in 2011 by which readers of *Epilepsia* could access/download articles of interest. Initial data (from the last half of 2011) indicate an average of over 1,000 active app users per month, with the number of access/month rising to over 18,000 by the end of the year.

Philip Schwartzkroin and Simon Shorvon Editors-in-Chief Epilepsia



INTERACTIVE MEDIA REPORT





The plan to re-do the ILAE website started in 2010. The purpose was to improve the quality of the website, its ease of use, the accessibility of the information, and to make the website more informative and more useful to the community served by ILAE. The new website was put in place on 1 August 2011. The new website has been operating well and was generally well received.

Changes in 2012

The Web Manager, Deb Flower, has been in place working the equivalent of three days/week since November 2011. She has been very effective with the maintenance of the website, which is updated several times per week. At the beginning of 2012, we started working with a programmer, Steve Shane. This has considerably improved our responsiveness and ability to solve web-related programming issues promptly.

During 2012, we redesigned the home page, as we felt that the original design did not leave enough place for news items and put too much emphasis on the ILAE meetings. We kept the general structure of the website intact but improved its aesthetics. The center of the page is now dedicated to news, with major news items at the top and regular news sections below. We make an effort to obtain news items from Commissions, Chapters, individuals and Congresses, and all news items are updated regularly, rarely staying more than a few weeks. We have also considerably increased the number of photographs, particularly of individuals.

Our efforts to improve the visibility of the website (search engine optimization) were not very successful. We spent some funds and energy with a company specializing in this field but came to the conclusion that there was no miracle in this respect. It appears that one of the important aspects of improving searchability is to frequently post new contents on the site. As we are doing this, we hope that our visibility will increase.

We have changed the search engine for searches within the website to use a Google-based search engine. This is available for a small fee and has resulted in much better and much faster searches.

We reorganized the listing of Past Congresses and consolidated the materials available from such Past Congresses to improve its accessibility.

Much posting on the main site and on commission sites dealt with the various elections being held during the year.

Other Media

We established an ILAE presence on Facebook and Twitter, where we currently have 126 "likes" and 134 followers, respectively. Facebook and Twitter are linked to all changes in the news section of the website.

Commission Sites

The Commission sites were put in place, but we have to admit that our aim of having each Commission manage

and update their websites has not generally worked out. Although some Commissions make a few changes to their website, these sites are not generally very active. We have taken the responsibility of updating these sites for Regional Congresses, elections and prizes. Additionally, we have added member pages to each site that provide a listing of the membership of each Commission and Task Force with a photo if one is available.

Surveys

During 2012, we put in place a system that allows placing a one-question survey when the website is accessed. These should be quick and simple enough to not be annoying and to encourage visitors to the website to answer them. This will help us understand the different types of visitors to the site and what type of information they are looking for. The first survey started in early 2013.

Plans for 2013

We feel that a solid and active website is in place. Our main activity will be to maintain and increase its information content and make it even more responsive to events related to epilepsy around the world. In this respect we will analyze the results of our surveys and determine, with the Executive Committee, if any changes are necessary.

Chapter information, including Chapter Officer and Member data and the information on the Chapter pages (e.g., country flag, Chapter website, Annual Congress dates), currently resides in an external Chapter database. The existing Chapter database will be altered so that the Chapter Officer and Member data will no longer be stored there but will be integrated into the League's membership database. This new solution will facilitate the updating of information by ILAE staff and Chapter leadership while allowing more use of the membership database capabilities.

We will continue to increase our presence on Twitter and Facebook.

We may want to consider better coordination and integration of the ILAE website and the Congress websites, which are currently independent and link to each other. From this point of view the ILAE website does not benefit from traffic on the Congress website and this is unfortunate.

Budget

The 2013 website budget is decreased by almost 15 percent over the 2012 budget taking into account that the larger changes are now in place, while still allowing for continuous improvement and new projects.

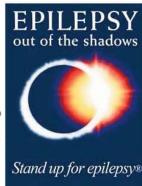
Jean Gotman, Director of Interactive Media Priscilla Shisler, Administrative Director

GLOBAL CAMPAIGN REPORT



The year proved to be as busy as ever, with many activities going on.

Activities included the development of a central message which involved many people all over the world. One issue that had to be taken into account was the feasibility of translating it in as many languages as possible, without losing its original meaning. In the meantime the trademark



registration process has been completed (see above). The slogan, "Stand up for Epilepsy," depicts the need for all of us to be actively involved in changing the lives of people with epilepsy for the better.

Demonstration Projects

Initiation of New Projects

The feasibility of a Demonstration Project was investigated in Cameroon and India, whilst projects were initiated in Ghana and Vietnam.

Cameroon – funds are being sought to implement this project. A Stakeholders Meeting took place and a protocol was developed.

Ghana – Within the WHO mhGAP program in close collaboration with ILAE and IBE a project was initiated in Ghana. A Stakeholders Meeting took place and a situational analysis is being drafted.

Vietnam – Also, within the WHO mhGAP program and in close collaboration with ILAE/IBE a project is being initiated, a Stakeholders Meeting took place and a situational analysis is being drafted.

India – The feasibility of initiating a project in India is being investigated.

Assessment of Country Needs and Resources on Epilepsy

In early 2011, a project to conduct needs and resource assessment specific to epilepsy in Tajikistan was initiated by the GCAE in collaboration with the WHO European Regional Office, and WHO Country Office Tajikistan.

A project has now been approved by IBE and ILAE with its main objective to improve and replicate the administration of the epilepsy need and resource assessment instrument that has been developed in Tajikistan in two more European countries over the next two years. Preparations for the selection of these two countries are being made.

Finalization Publication on Legislation and Epilepsy

This document has now been finalized and has been produced on CD. It will be formally launched at the beginning of next spring.

Organization of Stakeholders Meetings

Regional Stakeholders Meetings were organized in Africa (Nairobi, Kenya) and Asia-Oceania (Manila, Philippines) during the respective Regional Congresses. Such meetings took place in all Regions during this term of the Executive Committees of ILAE and IBE. The WHO Regional Advisors for Mental Health, the leadership of ILAE and IBE and Regional Stakeholders participated in all meetings during which ongoing and future campaign activities in the respective Regions were discussed.



Stakeholders meeting Nairobi



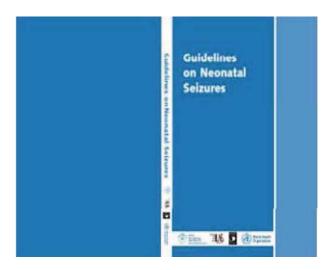
Stakeholders meeting Manila

Development Guidelines for the Treatment of Epilepsy in Childhood and Adolescence

These guidelines have been worked on in collaboration with the WHO Department of Child and Adolescent Health and Development. Evidence-based guidelines for the management of neonatal seizures in resource-poor settings have been completed and published.

GLOBAL CAMPAIGN REPORT (continued)

The guidelines have now been printed and are being disseminated through the ILAE and IBE offices.



Project on the Global Burden of Disease

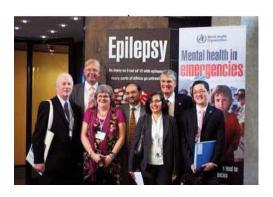
Within a new WHO Global Burden of Disease project, comprehensive estimates of the burden of epilepsy, its disabling sequelae and their role as a risk factor for other diseases and injuries are being developed. The Global Campaign Against Epilepsy is contributing to this project.

Participation in WHO mhGAP

The mhGAP is the WHO action program for low and lower middle income countries for scaling up services for mental, neurological and substance use disorders. An important strategy of mhGAP is to establish productive partnerships, to reinforce commitments with existing partners, and to attract and energize new partners. At present no single player has the expertise, funding or research and delivery capabilities to tackle the full range of issues related to mental healthcare on a worldwide scale.

As part of this strategy, the mhGAP Forum was established. The vision of the Forum is to provide effective and humane care for all with mental, neurological and substance use disorders. The goals are to improve service delivery, reduce treatment gap and increase financial and human resources for mental healthcare.

The ILAE and IBE are members of this Forum, and participated in its annual meetings, the third one of which took place in 10 October of this year.



2010



2011

Hanneke M de Boer Co-Coordinator Global Campaign

INTERNATIONAL DIRECTOR OF MEETINGS REPORT



Congress Report 2011-2012

Annual Congress Update

The ILAE Congress Staff managed five Congresses during the period July 2011 to November 2012. During that time, 10,004 attended the Congresses from over 110 countries worldwide, with 877 speakers and Chairs. The 240 people were assisted to attend these Congresses by means of bursaries awarded.

We were very pleased to embark on a new endeavor this year with the launch of the ILAE-IBE African Congress. The 1st AEC in Nairobi, Kenya in June 2012 was an outstanding success and marks the development of another Region for ILAE-IBE

Another stimulating new initiative is the European Forum on Epilepsy Research in 2013. This is the first time that a conference on epilepsy research will be supported and partially-funded by the European Union, and it will take place in Dublin during the Irish Presidency of the EU.

In tandem with the running of the Congresses during this period, the ILAE Congress Staff has been continuing with the careful planning and preparation for the International and Regional Congresses upcoming over the next years.

29th International Epilepsy Congress (IEC), Rome, Italy



28 August-1 September 2011

The 29th IEC took place at ROME 2011 the Rome Marriott Park Hotel. The Scientific Advisory & Organizing Committee

(SAOC) was chaired by Mike Glynn (Ireland) and Solomon L Moshé (USA), and comprised Emilio Perucca Congress Director, (Italy); Federico Vigevano Scientific Program Director, (Italy); Giovanni Battista Pesce (Italy) and Janet Mifsud (Malta). The main topics of the congress were "When do we consider epilepsy cured?," "Impaired consciousness in epilepsy,"
"Epilepsy during puberty – the wonder years," "Older, slowing down and seizing up - epilepsy strikes again,' "Predicting the unpredictable: the adverse effects of treatments," "Challenges in developing a new approach for classification in epilepsy" and "Avoiding epilepsy deaths," which was addressed in the Presidential Symposium. There were two postpresidential symposia entitled "Epilepsy Destroys Lives." In addition, sessions included The Prize Symposium, Parallel Sessions, Teaching Sessions, "How To" Series, Case-Oriented Learning Series, Video Sessions and Platform Sessions, complemented by Poster Sessions and Satellite Symposia. The Congress program was designated for up to 22 hours of European external CMĒ credits by ÚEMS.

Registrations numbered 3,963 from 114 countries. A total of 870 abstracts were received and are available online on the Epilepsia website. Poster Tours took place at lunchtime led by key experts. Thirty bursaries were awarded in equal measure to ILAE and IBE applicants. A reduced registration fee was available for delegates coming from lower income countries.

Several awards were presented during the Congress: the Lifetime Achievement Award, the Social Accomplishment Award, Ambassador for Epilepsy Awards, the Michael Prize and the Morris-Coole Epilepsia Prize.

The 29th IEC marked the high point of a year of activities arranged by the IBE to celebrate its Golden Jubilee, including the 'Epilepsy Without Words' photography competition, a poster display highlighting the initiatives and achievements of IBE's member associations and a Milestones Walkway – an exhibition of significant moments in the history of IBE. As part of the celebrations for the IBE Jubilee, there was a special event concert with the world-renowned Carabineri Band at the Auditorium Conciliazione, which was the venue of the Epilepsy Congress in 1961 when the IBE was founded.

9th Asian & Oceanian Epilepsy Congress (AOEC), Manila, Philippines 22-25 March 2012



The 9th AOEC took place at the SMX Convention Centre. The Scientific Organizing Committee (SOC) was co-chaired by Byung-In Lee (Korea), Robert Cole (Australia) and Josephine Casanova-Gutierrez (Philippines). The Scientific Program

was put together to be of great interest to all, encompassing recent scientific, clinical and social developments in the field of epilepsy. The topics for the main sessions were "Epilepsy genes and beyond," "The impact of epilepsy," "Epileptic networks and seizure propagation" and "Epilepsy and the developing brain." The IBE Epilepsy & Society program was developed by local and Regional Committees of IBE, and the main topics of the symposium focused on "Anxiety and depression in epilepsy," "The impact of epilepsy" and "Empowering people with epilepsy."

Registrations numbered 1,360 from all parts of Asia and Oceania, as well as the rest of the world. A total of 162 abstracts were received. Thirty-two bursaries were awarded. A particular emphasis was given to those coming from developing Regions, which are locally active in the field of epilepsy. Funding for these awards was provided by the IBE, the ILAE and the ILAE-CAOA.

Several awards were presented during the Congress: Outstanding Person with Epilepsy Awards and the Tadokoro Award.

INTERNATIONAL DIRECTOR OF MEETINGS REPORT (continued)

The Welcome Reception following the Welcome Ceremony on 22 March was sponsored by the Philippine Department of Tourism. It took the form of a "Pagdiriwang" or traditional Philippine celebration with food stalls, musicians and dancers.

1st African Epilepsy Congress (AEC), Nairobi, Kenya 21-to 23 June 2012



The 1st AEC took place at the Crowne Plaza Nairobi. The Scientific and Organizing Committee, along with members of the ILAE's Commission on African Affairs and the IBE African

Regional Committee, compiled the Scientific Program of 40 sessions with 45 speakers. The Congress had a different theme per day:

- Day One: Diagnosis, management and special epilepsy populations
- Day Two: Management gap and comorbidities; Research in Africa
- Day Three: Primary healthcare and the way forward in the African Region.

Amongst the program was a World Health Organization session entitled "The World Health Organization MHGap initiative: Next steps in Africa." The program contained a "Meet the past presidents" session, where past presidents of ILAE and IBE gave a reflection of their experiences on the progress and challenges of epilepsy in Africa and the developing world during their tenure. This presented the audience with a unique, personalized view from each of the past presidents. Sanofi held a satellite symposium during the Congress, "Developing Access to Care for people with epilepsy: sharing field experiences."

Registrations numbered 291, with 209 coming from Africa. A total of 60 bursaries were awarded by ILAE and IBE to people from Africa.

The Hon Prof Peter Anyang' Nyong'o, MP, Minister for Medical Services opened the Congress during the Welcome Ceremony on 20 June. Larry Asego, a Kenyan media personality, acted as Master of Ceremonies for the evening. Also present were a local group 'Youth on the Move' who performed a song and dance (YotM is an initiative of, by and for the youth with epilepsy that combats the misunderstanding and prejudices about epilepsy). Entertainment was provided by Bomas of Kenya, who put on a display of traditional dancers and music.

10th European Congress on Epileptology (ECE), London, UK 30 September - 4 October 2012



The 10th ECE took place at the ICC London ExCeL. The four main topics selected by the ILAE Commission on European Affairs were: "Imaging and pre-surgical evaluation"; "AED clinical pharmacology in adults and children"; "Basic and translational epileptology" and "Epileptology"

epileptology" and "Epileptology and psychiatric problems in adults and children." The Chairs' Symposium was entitled "The borderland of epilepsy." The Plenary themes had associated Platform and Poster Sessions. The Scientific Advisory Committee, chaired by Simon Shorvon (UK), constructed a full and high quality program of around 300 presentations. There were four main sessions, six special symposia, 42 sessions, 31 ECE forums, nine sponsored symposia, three debates, 15 Platform Sessions and three "how to do it" sessions. A coordinated teaching course on the "Causes of epilepsy" was held at the end of the Congress.

Other highlights of the Congress comprised the Nobel Lectures, daily talks given by a Nobel Laureate or Field Medallist, "100 barbiturate years," a special symposium to celebrate the centenary of the discovery of the antiepileptic action of phenobarbital and the Epilepsy Olympiad, an epilepsy tournament for competing National Chapters – won by Ireland. The Congress program was designated for up to 21 hours of European external CME credits by UEMS.

Registrations numbered 3,724 from 96 countries in all parts of Europe and the rest of the world. A total of 859 abstracts were received. There was a strong focus on posters, including Poster Tours led by key experts and Best Poster presentations in the poster area daily. Sixty-eight bursaries were awarded by the ILAE Commission on European Affairs.

Several awards were presented during the Congress: European Epileptology Award, British Branch Excellence in Epilepsy Award, Morris-Coole Epilepsia Prize, CEA Service Award, CEA Education Award and the CEA Young Investigator Award.

The ILAE, through the Task Force on Sports and Epilepsy, launched an exciting and innovative new photography exhibition during the Congress, "Stand up for Epilepsy." The collection features people with epilepsy alongside some of the biggest names from the sporting world, and was on display for the duration of the Congress.

INTERNATIONAL DIRECTOR OF MEETINGS REPORT (continued)

An historical exhibition entitled "The beginning of the end of the falling sickness: epilepsy and its treatment in London 1860-1910" was on display for the duration of the Congress. This exhibition, compiled and prepared by Simon Shorvon and Louise Shepherd, was composed of 70 items relating to the development of epileptology in London 1860-1910.

7th Latin American Congress on Epilepsy (LACE), Quito, Ecuador 14-17 November 2012



The 7th LACE took place at the Hilton Colon Quito Hotel. The Scientific Advisory and Organizing Committee, chaired by Lilia Núñez Orozco (Mexico), Marco Tulio Medina (Honduras) and Patricio Abad (Ecuador),

planned the scientific program incorporating scientific and social topics presented by a wide range of speakers. Plenary sessions were on the following topics: 'Diagnosis of non-refractory epilepsies in children,' "Diagnosis in non-refractory epilepsy in adults," "Treatment of non-refractory epilepsies in children," "Treatment of epilepsy in adults," "Developmental brain disorders and epilepsy (I Diagnosis)," "Epilepsy in the elderly," "Invasive diagnosis, surgery and results," "Transition in the treatment of epilepsy: child, adolescent and adult," "Temporal lobe memory and epilepsy" and "Extra-temporal epilepsy," while the Presidential Plenary Session (ILAE/IBE/PAHO/WHO) focused on "Epilepsy for the Americas." The program was completed by Discussion Groups and Symposia. A number of educational courses organized by the Latin American Epilepsy Academy (ALADE) took place on Neurobiology, Pharmacology, Genetics of epilepsy, and EEG and Semiology of seizures. For the IBE Day on 14 November, the Ecuadorian member of IBE (National Epilepsy Centre – Association of Parents of Children with Epilepsy) designed a program in line with its objectives of expanding knowledge about the complexities of epilepsy in children, that relates to health and education professionals as well as families, with a symposium on "Schooling and epilepsy" and a seminar on "Neuropsychomotricity, a tool in the treatment of children with epilepsy.

Several planned activities took place during the Congress introducing and setting in motion the implementation of the PAHO 'Strategy and Plan of Action on Epilepsy' (Estrategia y plan de acción sobre epilepsia) which aims to prioritize epilepsy in healthcare throughout the Americas.

Registrations numbered 666 from all over Latin America and the rest of the world. A total of 148 abstracts were received from 19 countries. Forty-nine bursaries were provided to young applicants who submitted an abstract of high scientific quality, to assist them with travel, registration and accommodation expenses. There was a Concert at the Casa De La Música on 15 November.

European Forum on Epilepsy Research (EFER), Dublin, Ireland 25-27 May 2013



The EFER will take place at the Convention Centre Dublin. The Forum, an activity of Epilepsy Advocacy Europe, Joint European Task Force of ILAE and IBE, is a groundbreaking collaborative

research conference, partially-funded by the 7th Framework Program of the European Commission in conjunction with the Irish Presidency of the European Union. This is the first time that the European Union has sponsored a conference on epilepsy research. It will bring together leading epilepsy researchers and policy makers in Europe.

The primary focus of the Congress will be to foster support for research from the European Union Presidency. The Congress will address three themes which have been developed in line with the funding application. The themes will be: Research priorities; European-wide collaboration; and Training. The program will comprise five research topics, two topics on stigma and two on standards of care. The Program Committee and Scientific Advisory Committee of the Congress consist of individuals who are experts in one or more of the outlined themes. The EFER aims to discuss the opportunities for coordinated, targeted and precise innovative research efforts that would build on the significant gains made by basic and clinical research in the past; to address the optimal standards of care for persons with epilepsy which are still unequally structured in Europe; and to develop innovative research into strategies to raise public awareness of epilepsy and to reduce the stigma associated with the disease.

The Congress will target an audience of key stakeholders including politicians, policymakers and advocacy groups. Members of key Chapters and associations will also be invited and the Meeting will be open to participants from around the world. Between 300-500 delegates are expected. Accommodation for the Congress will be in hotels in the city center, within walking distance of the venue. Dublin has a public transport system of buses, trams and local trains. The EFER will have an Opening Dinner, which may be held at the Mansion House (the official residence of the Lord Mayor of Dublin).

INTERNATIONAL DIRECTOR OF MEETINGS REPORT (continued)

30th International Epilepsy Congress (IEC), Montreal, Canada 23-27 June 2013



The 30th IEC will take place at the Palais des Congrès de Montréal, which is located in the center of Montreal, 20 minutes from the city's international airport, and surrounded by

plenty of hotels to suit all budgets.

The International Organizing Committee (IOC) along with the International Advisory Committee (IAC) and the ILAE Education Commission has put together a comprehensive scientific program appealing to anyone working in the field of epilepsy. The program covers a diverse range of topics that encompass recent scientific, clinical and social advancements in the field of epilepsy all delivered by world-renowned speakers. In addition to the Presidential Symposium, main and parallel sessions, new additions to the program include Meet the Experts sessions, lively controversies and an Epi-Quiz. Highly informative teaching sessions and the popular Prize Symposium complete the program along with engaging Platform Sessions and topical satellite symposia.

The online registration system opened in Autumn 2012. Reduced registration fees are available for "Allied Health Professionals" (AHP) or "Non-Medical Health Professionals." An additional discount of 50 EUR applies for IBE and ILAE members. The abstract system will open from late November 2012. Travel bursaries will be available. A reduced registration fee is also available for delegates coming from lower income

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



The 13th ECES will take place Epilepsy & Society at the Cankarjev Dom Cultural and Congress Centre (CD). The CD boasts a central location at

a walking distance from several hotels and the attractive Old Town.

The theme of the conference is "Break Down the Barriers and Stand Up for Epilepsy." The Organizing Committee is chaired by Thanos Covanis (Greece), Chair of the IBE European Regional Executive Committee, and members are Michael Alexa (Austria), Victoria Dimech (Malta), Matevż Krżan (Slovenia), Janet Mifsud (Malta), Seppo Sarkkula (Finland), Ljubica Vrba (Slovenia). The program comprises morning and afternoon sessions, a debate and group sessions.

Registration will open in December 2012. Posters are invited for presentation at the Conference and the online submission system will open in early 2013.

Future Congresses 2014, 2015, 2016

The ILAE Congress Staff is also currently working on arrangements for the 31st IEC in 2015, as well as the Regional Congresses taking place in 2014, 2015 and 2016.

Richard Holmes International Director of Meetings



TASK FORCE ON CLINICAL PRACTICE GUIDELINES

Task Force Chair:

Tim Pedley, Nathalie Jette, Jo Wilmshurst

Task Force Members:

Africa

1) Jo Wilmshurst, Co-Chair, (Cape Town)

Asia

- 1) Nobukazu Nakasato (Japan)
- 2) Yuping Wang (China)
- 3) Sanjeev Thomas (India)

Europe

- 1) Colin Dunkley (UK)
- 2) Eva Kumlien (Sweden)
- 3) Jozsef Janzky (Hungary)
- 4) Emilio Perucca (Italy)

Latin America

1) Horacio Senties (Mexico)

North America

- 1) Nathalie Jette, Co-Chair, (Canada)
- 2) Solomon Moshé (USA)
- 3) Timothy Pedley, Chair (USA)
- 4) Khara Sauro (Canada) PhD student
- 5) Samuel Wiebe (Canada)

Aims

- 1. Inventory of existing guidelines
- 2. Where are there gaps (no guidelines)?
- 3. Where is there a need for updated guidelines?
- 4. Where do existing guidelines provide conflicting recommendations?
- 5. What should be future processes followed in the development of epilepsy and EEG-related international guidelines?
- 6. How do we effectively disseminate guidelines to ensure update in practice?

Mission of the Task Force

To harmonize and facilitate the process of epilepsy guideline developments internationally and to identify where there are gaps in this area

Task Force Activities from July 2011 through July 2012

- 1. First Conference call (June 2012) and face to face meeting October 2012 (London, UK)
- Systematic review well under way (see attached minutes from first call and first face to face meeting for update)

Reported by Nathalie Jette

TASK FORCE ON EPILEPSY IN THE TROPICS

Task Force Members:

Pierre-Marie Preux, Chair (France)
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)

Mission of the Task Force

ILAE strongly reaffirms its will to contribute to decrease the burden of epilepsy worldwide, and in particular where this burden is greatest, i.e. in tropical areas. ILAE promotes a multi-disciplinary new Task Force on epilepsy in the tropics with the following aims, in conjunction with other recent or previous initiatives.

Aims

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
- work with the Global Outreach Task Force, to provide input to the ILAE Executive Committee, and to the ILAE Education Commission on initiatives related to epilepsy and seizures in the tropics
- 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
- liaise with the Education Commission in surveying educational needs in the tropics and advising on how best to address them.

Task Force Activities from July 2011 through July 2012

Despite no budget this year, the Task Force has had several activities. Meeting in Roma, the group agreed that the three main objectives of this Task Force would be: education, prevention and access to medication.

- The Latin-American Summer School on Epilepsy to be held in 2013 (LASSE VII) should be specifically devoted to the topic of this Task Force, that is: seizure and epilepsy in the tropics.
- Participation in the Congress of Nairobi on Epilepsy in Africa, presenting an update of Task Force activities.
- Update of literature review of epidemiology of epilepsy in Subsaharan Africa (paper in preparation).
- Submission of a European Union FP7 project on parasitoses and epilepsy with four Task Force members but failed.
- Participation in the Impact Epilepsy group meeting.
- Review of exiting initiatives on access to treatment in Africa (paper in preparation).

Recommendations for Future Work

Business meeting in Montreal in June 2013, literature review and synthesis on prevention of epilepsy in the tropics, alert paper on regulatory problems of phenobarbitone in the developing world.

Reported by Pierre-Marie Preux

TASK FORCE ON INSTITUTE OF MEDICINE



On 30 March 2012, the Institute of Medicine (IOM) released its much anticipated report on the epilepsies titled "Epilepsy Across the Spectrum: Promoting Health and Understanding." During the two years the IOM Committee worked on this project, more than 80 people provided presentations and personal stories about their experience with epilepsy and the frustrations of finding effective care. The report highlights gaps in the knowledge and management of epilepsy, and suggests actions to promote better understanding and care. The report is nearly 540 pages in length (available as a PDF at www.iom.edu/epilepsy), and it emphasizes that epilepsy should be thought of as a spectrum of diseases (the epilepsies).

The report has five key messages:

- Epilepsies are common and complex neurological diseases that affect health and quality of life, and the focus of treatment must go beyond control of seizures
- Effective treatments are available, but timely referral and access to quality treatments fall short everywhere. Better data are needed to improve epilepsy identification and quality of care
- Health professionals must be better educated about epilepsy and proper treatments
- Education efforts need to be sensitive to health literacy and cultural considerations
- The stigmas associated with epilepsy have to be eliminated.

Based on the testimony and findings the IOM Committee developed 13 recommendations involving improved surveillance and prevention, education for patients and families, accreditation of healthcare providers, and improved collaboration between patient advocacy and professional organizations to take "ownership" of these diseases.

Since the release of the report, has anything important happened? The simple answer is yes. To promote communication a synopsis of the report has been published in *Epilepsy & Behavior* and will be available as a free PDF download for 12 months (http://www.sciencedirect.com/science/article/pii/\$1525505012004465). A shorter summary along with an introduction is available in the December issue of *Epilepsy Currents* from the American Epilepsy Society (http://www.epilepsycurrents.org/doi/pdf/10.5698/1535-7511-12.6.243)

As the Committee noted, one of the most compelling aspects of their study was the testimony provided by patients and families, only a small portion of which could be included in the final report. The full testimony has been gathered, edited and is now available online

and is highly recommended reading (http://dx.doi.org/10.1016/j.yebeh.2012.10.003). In addition, in part due to the IOM report, the U.S. Centers for Disease Control (CDC) published findings in the November 15 issue of its Morbidity and Mortality Weekly Report (MMWR) featuring their estimates of epilepsy prevalence and discussion of treatment gaps and access to specialty care for the first time in 20 years (http://www.cdc.gov/mmwr/preview/mmwrhtml/mm6145a2.htm?s_cid=mm6145a2_w). Furthermore, several sub-committees have been formed as part of the original Vision 20/20 group, one of which is creating a simple screening tool that can be used by patients and caregivers to define when it is time to seek another opinion about epilepsy care. That tool is expected by the end of 2013.

While all these activities are exciting and show the immediate impact of the report on the epilepsies, it is important that we consider how to use the report internationally, especially in light of the European Written Declaration on Épilepsy and the Pan American Health Organization (PAHO) Strategy and Plan for Action. The IOM recommendations should be integrated into the PAHO initiative to improve care for people with epilepsies throughout the Americas, and the European initiative. The report documents the many problems of the epilepsies and provides objective evidence on how we must move forward. The report is an essential tool in our discussions with health agencies. There are many needs, and it will be critical for ILAE along with our sister organizations, including IBE and WHO, to identify which recommendations to initiate and implement first to have the greatest impact world-wide on taking care of patients with epilepsy. This will be a complex task with many voices involved, but with only so many resources to go around we will need to identify and focus on those strategies with the greatest and most immediate impact. It is essential that we work together with common goals and that we speak with one voice to deliver our message clearly and accurately to those allocating healthcare resources. This effort is just beginning. As our mission moves forward, we encourage the international epilepsy community to get involved locally or through the international organizations to achieve the League's mission that no one's life is limited by epilepsy.

Reported by

Gary W Mathern, Chair, Strategic Task Force

TASK FORCE ON SPORTS AND EPILEPSY

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)

Mission

The Task Force was born in July 2011. Two main goals were posed for the activity of the Task Force.

- 1) To seek out and foster opportunities for interactions with major sports authorities and organizations to increase awareness about epilepsy worldwide.
- 2) To increase awareness and participation of people with epilepsy in sports activities according to their capabilities and not limited by epilepsy.

Task Force Activities from July 2011 through July 2012

Meetings were in Rome IEC and Baltimore AES. The main activity of the Task Force has been constituted by the Photography Sport Project. The aim was to create a collection of images of famous sport 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 130 photos of about 50 sports have been collected. The sport personalities present in the collection are mainly Olympic or World Championship medalists. They have been presented in an exhibition at the recent ECE in London.

Task Force Future Activities

- To increase the visibility of the Photography Sport Project having the participation of other famous top level sport personalities.
- 2. To prepare exhibitions in San Diego AES and Montreal IEC meetings.
- 3. To print a book including all the photos of the athletes and PWE. The book will be distributed to the delegates at the Montreal IEC.
- 4. To prepare a position paper containing the ILAE official opinion about the medical and legal issues for the practice of sport for PWE.
- 5. To prepare ILAE official guidelines.

Reported by

Giuseppe Capovilla, Chair – Italy







JOINT AES / ILAE TRANSLATIONAL WORKSHOP TASK FORCE









A joint International League Against Epilepsy (ILAE) -American Epilepsy Society (AES) translational workshop to optimize and accelerate preclinical epilepsy therapy discovery was held in Customs House Hotel, London UK, on 28-29 September 2012. The incentive behind this initiative was the realization that, despite the significant advances and introduction of many antiseizure drugs into clinical practice, there are still unmet urgent needs to find treatments for drug-resistant seizures, as well as antiepileptogenic and diseasemodifying therapies for epilepsies and their comorbidities. The high cost associated with the discovery and validation of new therapies and the growing concern that a large number of preclinical discoveries fail to pass clinical testing have generated the concern that new strategies and methods are needed to optimize and de-risk the process of antiepilepsy therapy discovery. These issues were highlighted in a recently published joint AES/ILAE report [Galanopoulou et al. Identification of new epilepsy treatments: issues in preclinical methodology: *Epilepsia* (2012): vol 53(3):571-82]. The joint ILAE/AES effort to address these issues continued through the ongoing collaboration of two Task Forces: the Preclinical Epilepsy Drug Discovery Task Force of the ILAE Commission on Neurobiology (chaired by Terence O'Brien and Michele Simonato) and the AES Translational Task Force (chaired by Helen Scharfman and Steven Roper). Seven working subgroups were created to address specific topics, as outlined below, through a series of teleconferences, in preparation for the London workshop. 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 opened with welcome comments from the current presidents of the ILAE, Solomon (Nico) L Moshé, and the AES, Frances E Jensen, who emphasized the commitment of their organizations to support the goals of the workshop and the initiatives that would enhance and accelerate the discovery of new therapies for epilepsies and comorbidities.

Each working subgroup then presented its summary presentation and proposal followed by group discussions. Working group 1, chaired by Jacqueline French, outlined the common epilepsy syndromes that present clinical "gaps to care" or provide opportunities to test new antiepileptogenic therapies, and discussed whether the existing animal models and preclinical behavioral tests may predict a drug's efficacy and tolerability in human patients. Working group 2, chaired by Aristea Galanopoulou, discussed the optimization of technical and methodological aspects in the conduct and reporting of preclinical studies that assess pharmacological and nonpharmacological

treatments, the regulatory requirements that need to be met, and the infrastructure developments that would be helpful to realize these goals. Working group 3, chaired by Karen Wilcox, addressed the specific challenges in developing, validating and meeting regulatory expectations for treatments targeting drugresistant seizures. Working group 4, chaired by Asla Pitkanen, presented a description of an optimal preclinical design for antiepileptogenesis studies, and discussed the challenges and possible next steps to facilitate the process. Working group 5, chaired by Amy Brooks-Kayal, highlighted the complex interactions between epilepsies and comorbidities and presented a critical overview of the current state of preclinical testing for anti-comorbidity treatments. A proposal for improving the existing infrastructure and resources was also included. Working group 6, chaired by Jerome (Pete) Engel Jr, identified the needs and strategies for the discovery and validation of biomarkers for epileptogenicity, epileptogenesis, and pharmacoresistance. Working group 7, chaired by Michele Simonato and Terence O'Brien, presented a proposal for multicenter preclinical trials and criteria to select candidate therapies for transition to clinical testing.

Invited speakers from 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 antiepilepsy 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 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.

To carve a roadmap to achieve the goals, a panel discussion was planned to set priorities, goals and next steps. Panelists included representatives of the sponsors of the London workshop, Nico Moshé (ILAE), Frances Jensen (AES), Steve White (CURE), Roger Porter (Epilepsy Therapy Project), and Daniel Smith (Autism Speaks), Vicky Whittemore as a representative of the NINDS, as well as two international investigators involved in antiepilepsy therapy discovery, Emilio Perucca and Terence O'Brien. The following were agreed as the primary outcomes of the meeting.

Vision:

To develop transformational new treatments for people with epilepsy that address the current major clinical gaps in care by 2025, in particular:

1. Antiepileptogenic and disease modifying treatments.

JOINT AES / ILAE TRANSLATIONAL WORKSHOP TASK FORCE (continued)

- 2. Drug resistant seizures.
- 3. Therapies for comorbidities.

It was noted that achieving #1 may also address #2 and #3.

The 5 primary next steps to achieve this vision are to:

- 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 preclinical 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.

The workshop was organized by Drs French, Galanopoulou, O'Brien, and Simonato, was 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 to the working groups 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 Pitkanen, 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,

Karen S Wilcox. The summaries and recommendations of the proceedings of the London workshop will be published in a special supplement in *Epilepsia*.

ILAE/IBE JOINT TASK FORCE, EPILEPSY ADVOCACY EUROPE

The European Forum on Epilepsy Research will take place in Dublin, Ireland from the 25-27 May 2013. The Forum is a collaborative research conference, partly funded by the 7th Framework Programme of the European Commission in conjunction with the Irish Presidency of the European Union in 2013. This is the first time that the European Union has sponsored a forum on epilepsy research and it is a highly significant and ground-breaking occasion. The Forum aims to bring together leading epilepsy researchers, patients organizations, industry representatives and policy makers in Europe to discuss a coordinated strategy for epilepsy research into the future. With the next EU Framework Programme (Horizon 2020) due out in the next year, it is essential that the epilepsy research community outlines its needs and targets, and this Conference is the opportunity to do just that. Ultimately it is hoped that this Conference will lay down the most important aspects necessitating funding and improvement for epilepsy research into the future.

The ILAE/IBE Joint Task Force (Epilepsy Advocacy Europe) has developed the program for this conference, focusing on three main objectives:

 To promote and discuss the opportunities for coordinated, targeted and precise innovative research efforts that would build on the significant

- gains made by basic and clinical research in the past.
- To address the optimal standards of care for persons with epilepsy which are still unequally structured in Europe.
- To develop innovative research into strategies to raise public awareness of epilepsy and to reduce the stigma associated with the disease.





COMMISSION ON AFRICAN AFFAIRS

Commission Members:

Chair
Secretary General
Treasurer
Education Officer
Research Officer
Communication Officer
Liaison to GCAE
(Outreach)

Pr Amadou Gallo-Diop Dr Callixte Kuate Tegueu Dr Angelina Kakooza Pr Jo Wilmshirst Pr Paul Kioy Dr Birinus Ezeala Adikaibe

Pr Baba Koumare

Subcommissions and Members Task Force on Access to Care:

Dr Sammy Ohene, Ghana Pr Amara Cisse, Guinea

Aims

- a) To set up the organization of the Commission on African Affairs
- b) To strengthen the communication and ILAE global outreach campaign of the CAA
- c) To establish and strengthen the education activities of the CAA
- To improve the access to care for patients with epilepsy
- e) 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 2011 through July 2012

- 1. 1-3 December 2011: Participation in the Commission of Chairs meeting at Baltimore, USA.
- Commission meetings: We had the first meeting in 30 August 2011 during the 29th IEC (Marriott Rome Park Hotel, Italy). Communications among members of the ILAE/CAA were mainly through e-mails and during business meeting.

The second business meeting took place on 12 to 15 November 2011 at Marrakesh, Morocco during the XXth World Congress of Neurology (WCN) and focused on the preparation of 1st African Epilepsy Congress, the training session in Bamako-Mali and Nairobi-Kenya.

The 3rd meeting held in 20 June 2012 in Nairobi Kenya, during the first African Epilepsy Congress (1st AEC).

 November 2011: publication of the first newsletter of the Commission on African Affairs "EPILEPSY AFRICA."

- 4. January 2012: Preparation of the 1st African Epilepsy Congress (AEC), Nairobi, Kenya.
- March 2012: Publication of the second version of the CAA newsletter and the opening of africaepilepsy website.
- 6. 12-15 November 2011: CAA Executive meeting. The agenda focused on the organization of the 1st AEC, the Anglophone training session during the 1st AEC, Nairobi, Kenya, the Francophone training session planned for September 2012 in Bamako-Mali, joint meeting of the WFN, IBE and ILAE for visiting professorship in Africa. It was also agreed to reinforce the Education commission with Dr Youssoufa Maiga (Mali) and Pr Charles Newton (Tanzania).
- 7. February 2012: Children with Epilepsy meeting in Uganda. Nineteen African countries were represented, additional information collected from 30 African countries. Speakers came from ILAE / ICNA, International and Africa. The next meeting is schedule in Cape Town, South Africa in February 2013 on Cerebral Palsy / Epilepsy feedback. Reports and publications are underway, see CAA Newsletter / www.ICNApedia.org.
- 8. 20 June 2012: Regional Training courses (RTC) for juniors and trainees in Neurology. Done in collaboration with WFN/EFNS/IBRO/ICNA. We had international and African speakers on adult and pediatric neurology (CNS infections and metabolic diseases; adult epidemiological studies). Bursaries were offered to six trainees. We specially thank Eveline Sipido (EFNS) for the organization and coordination of this meeting. The next RTC will be in Dakar, Senegal in June 2013. Epilepsy will be one of the teaching items. The ILAE has to increase the number of bursaries (more funding) to attend the meeting especially when epilepsy is a subject for discussion/training. We then need more collaboration with EFNS, WFN, IBRO.
- 9. 1st African Epilepsy Congress (Nairobi, Kenya, 21-23 June 2012). A well thought out program has been created incorporating specialists from within the region along with international speakers. A wide range of pediatric and adult topics are covered as well as a mix of didactic lectures with interactive videos. Nineteen training doctors were granted bursaries under the CAA after 40 applications were received; additional bursaries came from IBE.

ILAE Chapter Convention: AG Diop opened the meeting and welcomed everyone. N Moshé outlined the wonderful achievement that is the 1st African Epilepsy Congress and urged all present to continue to work together for the benefit of Africa. He suggested that ILAE's Commission on African Affairs (CAA) should work with the World Federation of Neurology, the European Federation

COMMISSION ON AFRICAN AFFAIRS (continued)

of Neurological Societies and the International Child Neurology Association to generate programs, for example long distance education, and to encourage the exchange of expertise. During the Commission meeting, the Education Subcommittee was expanded to encompass representatives from Francophone countries, Anglophone- and Portuguese-speaking countries.

- Pauline Samia (Kenya, pediatric neurology)
- Mehila Zebenigus (Ethiopia, adult neurology)
- Yohannes Woldeamanuel (Ethiopia, adult neurology)
- Soda Diop Sene (Senegal, adult neurology)
- Moustapha Ndiaye (Senegal, pediatric neurology)
- Manuel Cruzeiro (Angola, paediatric neurology).

Their roles are to support the educational activities and promote education in their Regions, to expand the adult neurology training needs and capacity database, and to assist with organization of training meetings.

Accomplishments from July 2011 through July 2012

- Organization of the 1st African Epilepsy Congress in Nairobi, Kenya on 21-23 June 2012
- Publication of two news letter "Epilepsy Africa" both soft and hard copy.

Recommendations for Future Work

- Increase the number of African Chapters
- Regular publication of the regional newsletter
- Update the GCAE document in French, English and Portuguese
- Epilepsy training courses should be organized in French, English and Portuguese
- Provide the list of epilepsy training centers in Africa and organize the visiting professorship in these centers.

Reported by

Callixte Kuate, Secretary-General

COMMISSION ON ASIAN AND OCEANIAN AFFAIRS (CAOA)

List of Members and Officers (Table 1 and 2) Table 1. Officers of CAOA (2009-2013)

Chair Secretary Treasurer Information Officer Members Byung In Lee (Korea) John W Dunne (Australia) Jing-Jane Tsai (Taiwan) Sunao Kaneko (Japan) 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 CAOA. The composition of ASEPA is shown in Table 2.

Table 2. Officers of ASEPA

(2007-2011)

Chair
Secretary
Members
Chong Tin Tan (Malaysia)
Andrew Bleasel (Australia)
Gourie Devi (India)
Yushi Inoue (Japan)
Weijing Liao (China)

Shih Hui Lim

Ex-Officio Byung In Lee (Chair, CAOA)

(2011-2015)

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 CAOA)

Chong Tin Tan

(Malaysia, Immediate past president,

ASEPA)

2. Aims and Missions of CAOA

(1) Aims

To develop, stimulate, and coordinate the epileptology agenda in the Asian and Oceanian Regions.

- (2) Missions
- To advance and disseminate knowledge concerning the epilepsies throughout the Asian and Oceanian Region

- b. To improve education and training in the field of the epilepsies in Asia via the formation of the Asian Epilepsy Academy
- To organize the Asian Oceanian Epilepsy Congresses together with the International Director of Meetings (IDM) and IBE's Regional Executive Committees
- d. To facilitate clinically relevant epilepsy research in
- e. To serve as a link between ILAE, IBE, WHO, regional medical organizations to promote prevention, diagnosis, treatment, advocacy and care for all persons suffering from these disorders in the Asian and Oceanian Region
- f. To promote the activities of local Chapters, encourage similar policies and administrative structures and facilitate their involvement within the global ILAE agenda
- g. To review epilepsy services and the size of the treatment gap in each country and aim to improve the former and reduce the latter

3. Action Plans of CAOA: 2009-2013

The following were formulated in the CAOA business meeting at Seoul, 26 September 2009, and presented/accepted at the Commission Meeting of ILAE in Paris, 22-23 October 2009

- Construct CAOA and ASEPA website with its link with ILAE Web and regional Chapter's Web, and publish Newsletter
- (2) Enhance education and training efforts and activities
 - (i) continue to provide teaching courses and workshops in Regions in need
 - (ii) provide epilepsy fellowship (~6 months) for the nurturing of future epilepsy specialists of the Region
 - (iii) continue to conduct EEG certification examination for the purpose elevating the standard of EEG recording and interpretation skills
- (3) Organize the Asian and Oceanian Epilepsy Congresses every two years
- (4) Stimulate Clinical and Translational Research
- (5) Promote New Chapter Formation
- (6) Facilitate Global Campaign Against Epilepsy (GCAE) activities
- (7) Facilitate Interactions and Communications among Chapters and Commissions
- (8) Initiate the "Asian and Oceanian Outstanding Achievement Epilepsy Award"

COMMISSION ON ASIAN AND OCEANIAN AFFAIRS (CAOA) (continued)

4. CAOA - Achievements (July 2011-June 2012)

- (1) Communications and Business Meetings
 - (a) Commission Chair Meeting at the AES in Baltimore, MD, 2 December 2011
 - (b) 9th AOEC-SOC meeting at 29th IEC at Rome, 28 August 2011
 - (c) CAOA-ASEPA Joint Business Meeting during the 9th AOEC on 21 March 2012, in Manila, Philippines
 - (d) Chapter Convention at the 9th AOEC in Manila, Philippines, 22 March 2012
 - (e) Award Dinner of AOEA(Asian and Oceanian Outstanding Epilepsy Award) at the 9th AOEC in Manila, Philippines, 23 March 2012
 - (f) Interactions with individual regional chapters
 - Mongolian chapter (Dr A Tovuudorji): CAOA support for the project of reducing Treatment Gap in Mongolia. Plan to have MES – ASEPA Congress in September 2012, in UB
 - (ii) Bangladesh chapter (Dr. Mannan): feasibility of a demonstration project for Treatment Gap
 - (iii) Support for the First Advanced Clinical Epileptology Courses in Chengdu, China, on 7-14 August 2011
 - (iv) Inaugural congress of Sri Lankan Chapter, Colombo, Sri Lanka, on 19 September 2011
 - (v) involved with the organization of Korean Epilepsy Congress in Songdo, Korea, on 7-9 June 2012
 - (vi) Inauguration meeting of Sri Lankan Chapter,
 - (g) Interactions with other Epilepsy Organization of the Region
 - (i) Joint symposium with Infantile Spasm Society at the Annual Congress in Tokyo, Japan, on 18-19 February 2012
 - (ii) Joint symposium with Asian Epilepsy Surgeons Society(AESC) at the Fifth Annual Congress in Hong Kong, 10-12 November 2011

- (2) Information Committee Activities (Chair: Sunao Kaneko)
 - (a) CAOA-Website: http://www.caoa-epilepsy.org
 - (i) Linked to ILAE and IBE websites, and to each Chapter
 - Source of information and a tool of communications
 - (ii) Organization of Information Committee
 -Information officers of major Chapter
 - -business meeting during the 9th AOEC in Manila, Philippines, on 23 March 2012
 - (b) Groundwork for the Publication of CAOA newsletter. The first CAOA newsletter was published in December 2012
- (3) Research Task Force(Chair: Patrick Kwan)
 - (a) RTF business meeting at Taipei, Taiwan, on 1 July 2011
 - (i) Scope of action: Improve research infrastructure
 Understand etiologies and epileptogenesis
 Lessen psychosocial comorbidities
 Achieve better treatment outcomes
 - (ii) Preparation of CAOA Research Priority Document to publish in *Epilepsia*, in progress
 - (b) Precongress basic research program in collaboration with ASEPA at the 9th AOEC in Manila, Philippines on 21 March 2012
- (4) GCAE Task Force (Chair: Ernest Somerville)
 - (a) Compiled a register of currently available GCAE activities in Asia and Oceanian Region
 - (b) Provided a means of activating communications among Chapters
 - (c) Promoted closer interactions with Global Campaign website and CAOA-website
 - (d) Provided services for the diagnosis and education in selected regions having severe treatment gaps
 - (e) Continued support for Lao and East Timor's projects
 - in Lao project, education and training of young neurologists or internists are carried by CT
 - in East Timor project, doctors, nurses, and paramedics were educated and trained by ES

COMMISSION ON ASIAN AND OCEANIAN AFFAIRS (CAOA) (continued)

- (f) Provided education and training of MDs and nurses in resource poor countries
- (g) Groundwork for the implementation of a Demonstration Project in the Region - communication with Bangladesh and Myanmar Chapter
 - Planning to have an Epilepsy Workshop in Yangon, Myanmar in March 2013, during which a project will be discussed in more detail
- (5) Asian and Oceanian Epilepsy Congress
 - (a) 9th AOEC in Manila, Philippines on 22-25 March 2012 (Co-Chairs: BI Lee, J C-Gutierrez, R Cole)
 - Attended by 1,216 delegates
 - 77 local and international speakers for the main scientific program and 23 local and international speakers for the epilepsy and society meeting
 - Scientific programs were evaluated as excellent
 - Logistics and progression of Congress was evaluated as excellent
 - (b) 10th AOEC in August 2014
 - Singapore was selected as the venue for the 10th AOEC
 - 10th AOEC SOC meeting was planned to be held at the ECE in London, UK, on 30 September 2012
- (6) ASEPA (Chair: Shih Hui Lim)
 - (a) Conferences organized by Specialty Society/ ILAE Chapter endorsed by ASEPA
 - Chinese Summer School by CAAE in Chengdu, China, 7-14 August 2011
 - support two speakers
 - 5th Annual Congress of AESC in Honk Kong, 10 November 2011
 - CAOA-AESC Joint Symposium on "Epilepsy Surgery of Frontal Lobe Epilepsy"
 - International Symposium on Neonatal Seizures and Related Disorders (ISNS) by Infantile Seizures Society (ISS) in Tokyo, Japan, 18-19 February 2012
 - CAOA-ISS Joint Symposium on "Surgery of Catastrophic Epilepsy in Infants"
 - Korean Epilepsy Congress 2012 in Incheon, Korea, 7-9 June 2012

- Participation in the Congress as representatives of ASEPA and CAOA
- (b) Conferences co-organized by ASEPA with ILAE Chapters
 - 2-3 July 2011, in Taipei, Taiwan, Title: Antiepileptic Drugs
 - 2 November 2011, in Bali, Indonesia, Title: EEG Refresh Course
 - 23-24 February 2012, in Cochin, India, Title: EEG Teaching Course (ANZAN format)
- (c) ASEPA Workshops and Lectures during the 9th AOEC in Manila, Philippines,
 - ASEPA Precongress Workshop(22 March 2012)
 - Clinical Epilepsy (organized by P Kwan), Title: Drug Resistant Epilepsy
 - Basic Science (organized by T O'Brien), Title: Translational Research
 - Masakazu Seino's Memorial Lecture on 22 March 2012
 - By J Gotman on "High Frequency Oscillations: A New Marker of the Epileptogenic Zone"
 - ASEPA Didactic Lectures
 - By Byung-In Lee, Title: Classification of Seizures and Epilepsy, 23 March 2012
 - By Sam Wiebe, Title: Psychological Issues in Epilepsy, 23 March 2012
 - By Akio Ikeda, Title: Brain Stimulations, 24 March 2012
 - By John Dunne, Title: The Role of EEG Monitoring in ICU, 24 March 2012
 - By Chong-Tin Tan, Title: Autoimmune Seizure Disorders, 25 March 2012
- (d) ASEPA EEG Certification Examination
 - Part 1 EEG Examination
 - 3 July 2011, Taipei, Taiwan
 - 3 November 2011, Bali, Indonesia
 - 22 March 2012, Manila, Philippines
 - 23 June 2012, Singapore
 - Part 2 EEG Examination
 - 3 November 2011, Bali, Indonesia
 - 25-26 November 2011, Xiamen, China
 - 18 December 2011, Taipei, Taiwan

COMMISSION ON ASIAN AND OCEANIAN AFFAIRS (CAOA) (continued)

- 21 March 2012, Manila, Philippines
- (e) Fellowships for 2012
 - (i) Chunhong Chen (China) to Shizuoka, Japan under Epilepsy Research Foundation of Japan
 - (ii) Shouwen Zhang (China) to Shizuoka, Japan under Epilepsy Research Foundation of Japan
 - (iii) Nguyen Thai (Vietnam) to Kuala Lumpur, Malaysia under ASEPA
 - (iv) Abdus Salam (Bangladesh) to Trivandrum, Kerala, India under ASEPA
- (f) Published Proceedings of AOEC in Neurology Asia
 - Proceedings of 8th AOEC were published and its Electronic version is available: www.neurology-asia.org
 - Proceedings of 9th AOEC will be published soon
- (7) Asia and Oceanian Outstanding Achievement Epilepsy Award (AOEA) (Chair: John Dunne)
 - (a) 2nd AOEA was awarded during the 9th AOEC in Manila, Philippines on 22 March 2012
 - Award Recipients: Leonor Cabral-Lim (Philippines) Yushi Inoue (Japan) Sunao Kaneko (Japan) Kurupath Radhakrishnan (India) Pongsakdi Visudiphan (Thailand) Liwen Wu (China)
 - (b) Award Dinner on 23 March 2012, Manila, attended by recipients of the first AOEA (2010) and second AOEA
- (8) Chapter Formation
 - (a) Sri Lanka became 19th Chapter of ILAE-CAOA on 1 September 2011 at 29th IEC in Rome
 - (b) Myanmar Epilepsy Society was organized in 2012 and submitted its Chapter application to ILAE
 - (c) Cambodia is in the process of organizing its epilepsy society

Summary of Accomplishment from 1 July 2011 through 30 June 2012

- 1. CAOA website is open and improving as expected
- Publication of CAOA newsletter has been underway (published in December 2012)
- 3. Publication of Research Priorities in Asia and Oceanian Region is under preparation
- 4. GCAE projects underway in the Region have been registered
- 5. Setting up a discussion group of GCAE of the Region
- 6. Exploring implementation of CAOA demonstration project in the Region
- 7. ASEPA initiatives have been most successful and accomplished its schedules as planned
 - Education and teaching courses
 - EEG teaching and training with certification exam
 - Publication of AOEC proceedings
 - Continued Fellowship Training Programs (four fellowships)
- 8. 9th AOEC was held with a grand success
- Interactions of CAOA with other epilepsy organizations (ISS and AESC) in the Region have been initiated to promote mutual recognition and collaborations
- Asian and Oceanian Outstanding Achievement Epilepsy Award (AOEA) is becoming an important recognition in the Region
- New Chapter formation is continuing to make progress
 - Sri Lanka became the 19th ILAE Chapter in the Region at the 29th IEC in Rome, 1 September 2011
 - Expecting Myanmar as the 20th ILAE Chapter in the Region in $2013\,$
 - Hope Cambodia becomes the next ILAE Chapter in either 2013 or 2015

In conclusion CAOA from 2009 to 2013 has achieved most of its aims according to the action plans made at the Initiation Meeting held on 26 September 2009, in Seoul, Korea.

The action plans of CAOA until the end of its term on 27 June 2013, follow:

COMMISSION ON ASIAN AND OCEANIAN AFFAIRS (CAOA) (continued)

- 1. Continue ASEPA initiatives including teaching courses/workshops, EEG teaching, training, and certification exam, publication of AOEC proceedings, and fellowship programs as planned
- Continue collaborations with ANZAN for EEG teaching programs
- 3. Continue its efforts to promote communications and interactions with individual Chapters, e.g., Indian Summer School, Chinese Summer School, Korean Epilepsy Congress, Taiwan Epilepsy Congress, Epilepsy Society of Australia, etc.
- 4. Continue its effort to promote interactions and collaborations with other epilepsy organizations in the Region, e.g., ISS and AESC
- Continue efforts for appropriate management and improvement of CAOA website
- 6. Continue publication of newsletter (twice/year)
- 7. Submission of CAOA-Report on Research Priorities in Epilepsy
- 8. Groundwork for the implementation of CAOA Demonstration Project for the Treatment Gap.

COMMISSION ON EUROPEAN AFFAIRS (CEA)

Commission Members:

Chair Secretary Communication Liaison Past Chair Treasurer Global Campaign Liaison Educational Liaison EAC - European Advisory Council – Secretary Ex-Officio, Basic Sciences Liaison EAC - European Advisory Council -Chair Ex-Officio, EC Liaison Ex-Officio, EC Liaison

Meir Bialer (Israel) Alla Guekht (Russia) Alexis Arzimanoglou (France) Michel Baulac (France) Eugen Trinka (Austria)

Athanasios Covanis (Greece) Helen Cross (UK)

Reetta Kalviainen (Finland)

Asla Pitkanen (Finland)

Torbjorn Tomson (Sweden) Solomon L Moshé Emilio Perucca

Aims

- Articulate internationally applicable guidelines for diagnosis and treatment of patients with epilepsy in Europe.
- 2. Stimulate and enhance education on the prevention, diagnosis and treatment of epilepsy.
- 3. Stimulate and enhance basic and clinical research in epilepsy in Europe.
- Work with European organizations to catalog current epilepsy care in Europe and determine its needs.
- 5. Prompt and facilitate initiatives that improve standards of comprehensive care (diagnosis, treatment and social care). Reduce the treatment gap throughout Europe.
- To help ensure that ILAE's organizational structure is efficiently and effectively dedicated to fulfilling ILAE mission.
- 2) Mission of the Commission

Aim 1 – Articulate internationally applicable guidelines for diagnosis and treatment of patients with epilepsy in Europe

Action: CEA liaisons: A Arzimanoglou, Communication; A Covanis, Global Campaign; H Cross, Education & EPNS; A Guekht, EFNS; A Pitkanen, Basic Science

Aim 2 – Stimulate and enhance education on the prevention, diagnosis and treatment of epilepsy

Action:

a) Established an educational agenda available for review on the CEA website with procedures for application for CEA support

- b) Continuing with the Migrating Courses in 2013-2014
- c) Coordinating the European Educational Courses. San Servolo: Basic Science, Pediatrics and Presurgical; Eilat: Pharmacology and AEDs; and Lyon: Stereo EEG alone or with EPODES
- d) Welcome new regional courses (e.g. Caucasian, Baltic Sea Summer School on Epileptology) that answer regional unmet needs

Aim 3 – Stimulate and enhance basic and clinical research in epilepsy in Europe

Action:

- a) Extensive dialogue via Epilepsy Advocacy Europe (EAE) with EU executives (directly and lobbying via various ILAE Chapters) aiming to give epilepsy research priority in EU funding
- b) CEA EU Symposium (Rhodes and London-ECEs)
- Support scientific conferences with European added value that publish post-conference proceedings (e.g. Status Epilepticus, inflammation in epilepsy)

Aim 4 – Work with European Organizations to catalogue current epilepsy care in Europe and determine its needs

Action:

Epilepsy Advocacy Europe (EAE) that is The CEA-EREC Joint Task Force (JTF) for Epilepsy Advocacy that obtained the following:

- a) Approval of the Declaration on Epilepsy in the EU Parliament
- Activate and support national CEA/EREC (ILAE/IBE) Chapters to obtain fair allocation of healthcare resources to epilepsy
- c) Ensure 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
- e) Organize a conference in Dublin, Ireland 25-27 May 2013 entitled: "European Forum on Epilepsy Research (ERF2013)" attended by all parties (lay, professional, political) to sensitize them to the above needs
- f) Catalyze collaboration on innovative research and demonstration projects

COMMISSION ON EUROPEAN AFFAIRS (CEA) (continued)

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) A CEA-CNA-CTA Joint Task Force (JTF) on regulatory issues of new AEDs [meeting in Rhodes-ECE (2010), Baltimore AES (2011) and Rome IEC (2011)]
- b) A JTF-EMA-FDA meeting on regulatory issues (Paris 17 November 2011)

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 & Secretaries (via Gus Egan ILAE – Dublin office)
- b) Establish ILAE Chapters in the three remaining European countries (Belarus, Bosnia and Iceland)
- Update CEA rules in accordance with the ILAE-EC proposed constitutional amendment

Awards

The following awards were presented during the 10th European Congress on Epilepsy in London, October 2012

- European Epileptology Award 2012: Christian Elger
- Young Investigators Regional Award: Pasquale Striano
- European Epilepsy Education Award: Alla Guekht
- European Epilepsy Service Award: Ann Little
- ILAE British Branch Excellence in Epilepsy Award: Chrysostomos (Tomis) P Panayiotopoulos

Commission Activities in 2012 and planned activities in 2013

CEA-Sponsored Courses/Symposia in 2012

- a. Young Scientists Symposium (Beer-Sheva, 7-11 January)
- b. 2nd Stereo-EEG Course (Lyon, 7-11 February)
- c. 6th Baltic Sea Summer School (Rostock, 8-13 June)
- d. 6th Migrating Course on Epilepsy (Porto, 10-15 June)
- e. San-Servolo Course on Pediatrics (Venice, 15-25 July)
- f. Dianalund Summer School on EEG & Epilepsy (Dianalund, 23-28 July)

- g. VIREPA-EEG SCORE Course (October 2012-February 2013)
- h. 4th Caucasian Summer School (Kakheti, Georgia, 2-7 September)

CEA-Sponsored Courses/Symposia in 2013

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

CEA-Sponsored Events for 2012-2013

- a. A European Chapter Convention during the London-ECE (30 September 2012) and Dublin during ERF2013 (25 May 2013) and thus, having a yearly dialogue between the CEA and the various ILAE-European Chapters
- 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 courses' 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

Reported by Meir Bialer

LATIN-AMERICAN REGIONAL COMMISSION

Commission Members:

Chair Secretary Treasurer LASSE Manuel Campos, Chile Eduardo Barragán (México) Patricia Braga (Uruguay) Esper Abrao Cavalheiro

(Brasil)

Franz Chaves Sell (Costa Rica)

Beatriz González del Castillo

(Venezuela)

Salvador González-Pal

(Cuba)

Šilvia 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

- To provide and promote epilepsy education and research with excellence, quality, efficient and humanistic approach for medical and non-medical professionals in Latin America.
- 2. To coordinate academic activities among the ILAE Latin America Region Chapters. 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 objective to improve the diagnosis and treatment of the epilepsies in Latin American, in the frame of our ILAE politics and its Strategic Plan.

Commission Activities from July 2011 through July 2012

1. 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 (1), which has the support of the International League against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE). The plan of action's aim is that the governments, through their Ministries of Health, with the support of PAHO, ILAE and IBE of the respective countries, support the creation of national programs and legislation about epilepsy, and improve those that already exist. The plan includes a goal of guaranteeing complete medical attention to every patient with epilepsy and at least four basic antiepileptic drugs (valproic acid,

carbamazepine, phenytoin and phenobarbital), in addition to actions that allow them to improve their quality of life in every area, so that they can be socially integrated and break down the associated stigma that comes with an epilepsy diagnosis. This challenge is already on course and it is a duty for everyone involved in the treatment of people with epilepsy to support the initiatives of the Strategic Plan, especially before the health authorities of the Latin American governments.

The main issue for us during 2011-2012 and our duty for the next few years is to develop epilepsy programs in all regional countries, and improve the prevention, diagnostic, treatment and quality of life in all people with epilepsy.

The Strategic Plan promotes partnerships with the International League Against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE), as well as international agencies, governmental and nongovernmental organizations, and other regional actors in support of the broad multi-spectral response needed for the execution of this strategy and plan of action. The main persons to reach this plan were Dr Jorge Rodriguez (PAHO), Dr Carlos Acevedo (IBE) and Dr Marco Medina (ILAE). We held a meeting in October 2011 in Honduras to prepare the strategies, with participation of authorities from WHO, ILAE and IBE.

Between 2011-2012 all ILAE and IBE Chapters in Latin America have made contact with the local Pan American Health Organization (PAHO), and together have visited the local health minister authorities in order to develop a "national epilepsy program" in each country in Latin America.

2. VI Latin American Summer School on Epilepsy (LASSE). February 2012, São Paulo, Brazil

Prof Esper Abrao Cavalheiro organizes LASSE with the support of many Brazilian colleagues (Drs Elza Marcia Yacubian, Americo Sakamoto, Fernando Cendes, etc). The LASSE VI received more than 50 young professionals from across Latin America for a full tenday course. Attendees learned through conferences and working on scientific projects. The program is supported by ILAE (20%); the rest of the resources came from the Brazilian Government and research agencies. Also the success of LASSE depends on the generosity of the many faculty (epileptologists) in great relationship with ILAE.

The previous LASSE were:

- a) The first LASSE: "Epilepsy: Translating basic knowledge into clinical applications," was held 4-14 February 2007
- b) The II LASSE: "Increasing knowledge and decreasing treatment gap," was held 7-17 February 2008

LATIN-AMERICAN REGIONAL COMMISSION (continued)

- The III LASSE: "Epileptogenesis in the developing brain: Basis for treatment and prevention', 4-14, February 2009
- d) The IV LASSE: "Epilepsy and Time," 1-9, February 2010)
- e) The V LASSE: "Epilepsy, behavior and cognition," 20 February to 1 March 2011

The LASSE VI was run 24 February to 3 March 2012, organized at the Santa Monica Hotel and Convention Center in Guarulhos, São Paulo, Brazil. The main topic was "Symptomatic Epilepsy: A critical updating."

A special event, during the LASSE VI, was a special award to Prof Arturo Carpio from Ecuador for his work devoted to the development of epilepsy treatment in Ecuador and Latin America.

3. Latin American Epilepsy Congress (LACE)

The LACE is our main regional activity organized every two years together with the International Bureau for Epilepsy (IBE) Commission in Latin America.

Quito, declared a World Heritage Site by the UNSECO, was delighted to receive around 800 attendees during the 7th Latin American Epilepsy Congress which took place 14-17 November in the Ecuadorian capital city. The event was sponsored by the ILAE and the IBE. The Latin American Epilepsy Commission and the American Academy of Epilepsy also played an outstanding role in the congress organization. The "Liga Ecuatoriana Contra la Epilepsia" was in charge of the local organization. The president of the local Committee was Dr Patricio Abad.

The Congress offered a high level scientific program. Many aspects of epilepsy were included, from molecular neurobiological principles, new therapeutic advances and a broad psychosocial agenda. Special attention was given to the PAHO/OMS initiative tied in with the Strategy and Action Plan for Epilepsy that urges to the Ministers of Health of the Region to make epilepsy a priority during the next decade. Also a review and validation of the new epilepsy classification and coding took place during the Congress. During the opening ceremony Dr Patricio Abad Herrera President of the Congress welcomed colleagues from Latin America and the globe. During his speech, he stressed the importance of seeing a strong Latin American union. "Speak with one voice," he asked, quoting president of the ILAE, Dr Solomon "Nico" Moshé. The importance of the academy in the Region has been growing in the last decade. This Congress was the right place to review all the achievements. The Congress served also as an opportunity to discuss and find new ways to reduce the epilepsy gap. Actually, as soon as the congress activities ended some of the newspapers and the TV media highlighted this

important event. We really hope that this event has fulfilled the attendee's expectations. We are looking forward to meeting all colleagues in the next LACE meeting.

4. Latin American Academy of Epilepsy (ALADE)

ALADE depends on our Commission and is its academic arm. The members of the ALADE Executive Committee are: Elza M Yacubian (Brazil), Jaime Carrizosa (Secretary, Colombia), Roberto Caraballo (Argentina), Loreto Ríos (Chile) and Guilca Contreras (Venezuela). They will serve from 2012 to 2015.

ALADE Mission: To provide and promote epilepsy education and research with excellence, quality, and efficient and humanistic approach for medical and non-medical professionals in Latin America. ALADE Vision: To promote and provide epilepsy education and research, aiming to improve the healthcare of people with epilepsy in the Region. Goal: The goal of ALAE is to promote epilepsy education and research in the Latin American region in order to improve healthcare of people with epilepsy.

Educational Activities – ALADE 2011-12

- a. 6th Latin-American Summer School On Epilepsy (LASSE VI) – Symptomatic Epilepsy: A critical updating – 24 February to 2 March 2012
- ALADE Course in Guatemala at the Medical School of the Universidad Estatal de San Carlos de Guatemala and Colegio de Médicos de Guatemala, 23 March 2012
- c. Launching of the e-book "EEG of Epilepsies" in Portuguese – São Paulo, 21 April 2012 – A oneday Course with the participation of Brazilian epileptologists and one Argentinian (Dr Roberto Caraballo) – 100 participants
- d. ALADE Course in Cuba 9-10 May 2012. Centro Internacional de Restauración Neurológica, 100 participants
- e. Selection of candidates Short Programs on Epileptology 2013
- f. Launching of the ALADE e-book in Portuguese distributed to participants of the Brazilian Neurology Congress in Goiânia, 4-8 August 2012
- g. Five courses during the Quito Congress: 1. Basic Science; 2. Pharmacology of epilepsies; 3. Course on EEG with the distribution of the e-book "EEG of Epilepsies" in Spanish; 4. Epilepsy throughout life with the distribution of the book and CD Las crisis epilépticas; 5. Genetics of epilepsy

LATIN-AMERICAN REGIONAL COMMISSION (continued)

5. Projects (Fellowship in epileptology and neurophysiology)

Four bursaries and 11 positions were offered in the call for applications after the budget approval (end of February 2012) with a deadline submission for applicants of 2011. Eleven applications were received and submitted for evaluation by ALADE Commission. Four bursaries were given at Universidade de Campinas (Brazil), Hospital de Clinicas de Ribeirao Preto (Brazil) and Hospital Ramos Mejias (Buenos Aires, Argentina). Further, those applicants not awarded with bursaries were offered the possibility of performing the fellowships in the remaining positions if they could obtain support from other sources.

6. Latin American Epilepsy Surgery Subcommittee

The members of this subcommittee are: Mario Alonso (Chair, Mexico), Americo Sakamoto (Secretary, Brazil), Carlos Barzallo (Ecuador), Manuel Campos (Chile).

The term of this subcommittee will be the same as the ILAE Commission on Latin American Affairs. The main goals of this subcommittee are improving the epilepsy surgery gap in Latin America, promoting education and research on epilepsy surgery and, working closely with the Latin American Academy of Epilepsy (ALADE).

The main achievement of this subcommittee has been the accomplishment of the first Fellowship in Epilepsy Surgery. Due to the underdevelopment of epilepsy surgery in many countries in the Region, we obtained ILAE support for one fellowship in surgical treatment of epilepsies (neurosurgeon), with Dr Mario Alonso at the National Neurological and Neurosurgical Institute of Mexico as coordinator.

7. Relationships with North American Subcommission:

The Latin American Commission worked together with the North American Commission and her chair and the Education Task Force of the North American Region. Our main goal was "the Strategy and Plan of Action on Epilepsies for the Americas" and also education, through the program "Partnering Epilepsy Centers in the Americas (PECA)." This program was developed with economic support from industry (UCB). It consists of visiting American professors in Latin-American epilepsy centers giving support for the development in specific areas of the epilepsies. Many countries were involved: Bolivia, Chile, Colombia, Costa Rica, Dominican Republic, Ecuador, Mexico, Paraguay, Peru, Uruguay, etc.

This year CAMELICE (Mexican League Against Epilepsy) received 20 fellowships for the best young researchers to attend the American Epilepsy Society Annual Meeting. The persons involved in these activities were

Eduardo Barragán and José Cavazos (AES). This reflects the possibility and the capacity of collaboration between not only two different Chapters but between Commissions and can be a model for planning this kind of support in the next Latin American Congress.

8. ILAE Chapters in Latin-America:

- a) New Chapters: Bolivia and El Salvador were incorporated officially as new Chapters at the International Epilepsy Congress in Roma (Italy).
 Dr Mario Camargo is the new president of ILAE Bolivia Chapter and Dra Claudia Valencia of El Salvador.
- b) Renewal of already established ILAE Chapters: Due to lack of recent and updated information on some Chapters, efforts were made to contact them and help them to give an update on their activities. A good example was Nicaragua. This country is again involved in our ILAE activities. Our tasks are not finished yet. We would also like to include new physicians in the management of each Chapter because one of our main duties is identification of new and young colleagues with interest in epilepsy in the Region. These people will be the next generation for the development of epilepsy care in Latin America.

9. Work Together with IBE (International Bureau for Epilepsy)

Our Commission has an excellent relationship with the Latin American IBE Commission (Lilia Nuñez, Chair, Mexico and Tomás Mesa Secretary, Chile) and the international Vice President (Carlos Acevedo, Chile). We work together in academic and social activities for development of epilepsy in the Region and together we organize the LACE. Our next step is to work on "The Strategy and Plan of Action on Epilepsies for the Americas" together with the World Health Organization (WHO).

Accomplishments (2009-2010)

- Successful activities on the Strategy and Plan of Action on Epilepsies for the Americas
- VI Latin American Summer School on Epilepsy (LASSE)
- Successful Latin American Epilepsy Congresses in Ecuador (2012)
- The Latin American Academy of Epilepsy (ALADE)
- Creation of the Fellowship in Epilepsy
- Establishing collaborative educational work with the ILAE North American Commission

LATIN-AMERICAN REGIONAL COMMISSION (continued)

Recommendations for Future Work

- 1) Continuation the Strategy and Plan of Action on Epilepsies for the Americas.
- 2) Support to LASSE as an important educational activity.
- 3) Support to the Latin American Congresses, as the main activity in our Region.
- 4) Continuous support to the Latin American Epilepsy Academy (ALADE) and the regional educational activities (i.e., Mesoamerica and Caribbean, Andean, etc.).
- 5) Develop fellowships in our Region for young epileptologists, where main epilepsy centers in the Region will be involved.

Summary: Based on this team work, the Commission on Latin American Affairs took a big step forward, becoming a mature Region with our main issue the Strategy and Plan of "Action on Epilepsies for the Americas." We must continue with the success of the Latin American Summer School on Epilepsy (LASSE), also with the Latin American Academy of Epilepsy (ALADE); establishment of new targets, like the epilepsy fellowship; development of a website with the main Conferences on LACE and the collaboration with the ILAE North American Commission. We still have several challenges in order to improve the prevention, epilepsy healthcare, education and research in our Region.

Reported by Manuel Campos

NORTH AMERICAN COMMISSION

Commission Members:

Chair
Past Chair
EC Liaison
Treasurer
Secretary
Education Officer

Sheryl Haut (USA) Jacqueline French (USA) Samuel Wiebe (Canada) Lionel Carmant (Canada) Sharon Whiting (Canada) Jaideep Kapur (USA) Amza Ali (Jamaica)

Liaison to Global Outreach Information Officer

William Theodore (USA) Nathalie Jetté (Canada)

Subcommissions and Members Task force on Access to Care:

Stigma Task Force: Natalie Jette (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 Trinka (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 Jette (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.

- The Education Task Force continues to focus on the Partnering in the Americas (PECA) program, as indicated below. The Task Force has also been working to fully develop visiting professorships to Africa, and has sponsored Spanish translation of a number of symposia at AES.
- 2. The Regulatory Guidelines Task Force met with EMA and FDA with future meetings planned. Specific activities are described below.

- 3. The Hispaniola Task Force has focused on the rebuilding and maintenance of the epilepsy clinic in Haiti, the neurocysticercosis project in the Dominican Republic (DR), and the epilepsy surgery program in DR. Expansion of the epilepsy clinic and neurocysticercosis projects are described below. The epilepsy surgery program in DR has continued to be successful.
- 4. The Caribbean Task Forces efforts culminated in the formation of the Epilepsy Society of the Caribbean, an ILAE Caribbean Chapter which received provisional acceptance in 2012.

 Additionally, the Task Force planned the 3rd regional meeting of the Epilepsy Society of the Caribbean, and continued many activities towards the development of epilepsy surgery in Jamaica. Specific activities are described below.
- The Stigma Task Force convened a large group of reviewers with representatives from the following ILAE Commissions: African, Asian Oceania, Latin American, European and North American. These experts are examining thousands of abstracts related to stigma, details below.
- 6. The newly formed PAHO Task Force has worked closely with the Latin American Commission and PAHO representatives towards shared goals.
- The IOM Task Force participated in the release of the IOM report and has been active in ongoing Vision 20-20 activities.
- North America Regional Congresses: The NAC has continued to sponsor an annual symposium at AFS

The current North American Regional Commission (NAC) was constituted in 2006, comprising English-speaking North American Chapters of Canada, the United States of America, and the English-speaking Caribbean (represented by Jamaica). The Mexican Chapter, although geographically in North America, is a member of the Latin American Regional Commission. The Commission's overall goal is to improve the delivery of epilepsy care throughout the Americas and the Caribbean.

Commission Activities from July 2011 through July 2012

Stigma Task Force: 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.

Education Task Force

PECA Program: The PECA program has continued to support partnerships between epilepsy centers in the Americas to promote education and improvements in

NORTH AMERICAN COMMISSION (continued)

epilepsy care. Over 20 visits have been completed through this program, with more in process.

Translation program: The NAC supported a pilot translation project at the AES Annual Meeting in 2011, funding a Spanish translation of the NAC symposium. We expanded the program at the AES Annual Meeting in 2012 with sponsorship of Spanish translation for the Annual Course, and two additional symposia including the NAC symposium on epilepsy classification.

Visiting Professorships to Africa: 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.

Task Force on Regulatory Harmonization: The Task Force worked in collaboration with the European Commission on 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 antiepileptic drugs.

Caribbean Task Force: This Task Force has focused on the development of the Epilepsy Society of the Caribbean, an ILAE Chapter, described more fully below. In addition, the Task Force helped organize the Caribbean Regional Epilepsy Congress in Antigua 2012, a successful meeting which was attended by healthcare professionals from 11 Caribbean islands. The NAC supported travel awards for junior Caribbean faculty to attend this Congress.

- Epilepsy surgery program in Jamaica: The Task Force has supported a telemedicine project between Yale and Jamaica, toward the development of an epilepsy surgery program in the Caribbean. The next steps include reverse training visits for a neurosurgeon and neuropsychologist from Jamaica to Yale
- Epilepsy program in Antigua: 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

Hispaniola Task Force:

- Haiti: Visiting professorships and telemedicine: The Task Force has performed bi-monthly visits in the region of Saint-Marc and Cange since March 2012 (Dr Carmant twice, Dr Elysee, Dr Bigelow and Dr Pierre-Louis once each). Dr Etienne will finish the six-visit program in February 2013
- Haiti: Neonatal seizure program: The new neonatal seizure program has included 45 neonatal EEGs interpreted by Dr Carmant
- Dominican Republic: Neurocysticercosis project: 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
- Dominican Republic: Epilepsy surgery: The Hispaniola Task Force as well as visits funded by the PECA program have been instrumental in the development of epilepsy surgery in DR. To date, more than 12 lesionectomies have been performed.

PAHO Task Force: 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 last year, a large meeting is planned for the Latin American Congress in November 2012, where the NAC will work 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.

IOM Task Force: The NAC, with the ILAE, participated in the release of the IOM report on epilepsy, and has continued to work with the 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.

Accomplishments (2011-2012)

Stigma Task Force:

- Data abstraction to begin Jan 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 Jette. Main Session: 'Stigma in epilepsy - who, why and what to do?'

Education Task Force: 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.

- Translation program: The NAC supported translation at the AES Annual Meeting in 2012 with sponsorship of Spanish translation for the Annual Course, and two additional symposia including the NAC symposium on epilepsy classification
- Visiting Professorships to Africa: Two of three funded African professorships have taken place very successfully during 2012, with the third scheduled for 2013. A call for proposals is underway for 2013 programs

NORTH AMERICAN COMMISSION (continued)

Task Force on Regulatory Harmonization: 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.

Caribbean Task Force:

- The 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 healthcare professionals from 11 Caribbean islands. The NAC supported travel awards for junior Caribbean faculty to attend this Congress
- Epilepsy surgery program in Jamaica: The Task Force has supported a telemedicine project between Yale and Jamaica, toward the development of an epilepsy surgery program in the Caribbean. The next steps include reverse training visits for a neurosurgeon and neuropsychologist from Jamaica to Yale
- Epilepsy program in Antigua: 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

Hispaniola Task Force:

- During each professorship visit to Haiti, the visiting faculty teaches medical students and family physician residents, as well as one local physician who sees patients with the team and who will complete formal EEG/Epilepsy training at CLIDEP after the January visit. It is anticipated that Partners in Health will equip each center with an ${\sf EEG}$ machine that will be linked to CLIDEP for telemedicine purposes
- Neonatal seizure project: Due to the high prevalence of neonatal asphyxia, a neonatal cooling program is being discussed, but maternal care needs to be improved as well
- Dominican Republic epilepsy surgery: To date, more than 12 lesionectomies have been performed.

PAHO Task Force:

Following an initial meeting last year, a large meeting took place in Quito, Ecuador with the Latin American Congress in November 2012. The NAC continues to work 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 provide insights into many projects consistent with the PAHO mandate that have been successfully completed during the past two terms. Additionally, the IOM report provides potential examples of regulatory progress in epilepsy care and this has been discussed.

The IOM Task Force: The NAC has been an active member of the epilepsy specialists IOM subgroup, working on the development of a screening tool for epilepsy.

Recommendations for Future Work

Stigma Task Force: The current work of the Stigma Task Force will be completed by the end of the current NAC term. Dissemination of results is anticipated through manuscript submission to Epilepsia, and presentation at the symposium in Montreal 2013. As this Task Force has been highly productive and the work very significant, renewal of this Task Force should be strongly considered for the next term.

Education Task Force: The PECA program has funds remaining, with a possibility of renewal by UCB. It is therefore anticipated that this program will continue into the next term. The focus of the program (professorships vs reverse visits) should be decided by the new Task Force members. Dissemination of results includes local publications related to each visit, and a manuscript in process. The future of the AES translation program will be decided after the upcoming AES meeting, where usage of the translation headsets will be monitored and compared to the previous year. It is anticipated that if this is a successful project, the cost going forward should be shared with AES.

Task Force on Regulatory Harmonization: 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 (the PEACE meeting) 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 early 2013 will help to direct these efforts.

NORTH AMERICAN COMMISSION (continued)

Caribbean Task Force: It is anticipated that the Epilepsy Society of the Caribbean will be ratified as a full Chapter member of the NAC in Montreal 2013. The NAC will help the new Chapter to publicize this across the Caribbean. The formation of this Chapter will enable a more unified effort for epilepsy education and clinical care across the English-speaking Caribbean, planned for the next term. The next regional epilepsy Congress is being planned for St Lucia in 2014.

Hispaniola Task Force: In March 2013, the Haiti visiting faculty plans to move to the southern region of the country, possibly Jacmel or Les Cayes. It is anticipated that this work will continue into the next term. The outcomes of this project will be included in the Education Task Force manuscript on the PECA program. We anticipate that Phase 2 of the cysticercosis project will result in significant findings to be published and improve awareness of the prevalence of cysticercosis in the area.

PAHO Task Force: 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.

IOM Task Force: It is anticipated that the NAC will continue to participate closely with the IOM healthcare provider group into the next term. It is recommended that the members of the next NAC consider the IOM recommendations when evaluating possible projects for the Commission to undertake during the next term.

Reported by Sheryl Haut



COMMISSION ON CLASSIFICATION AND TERMINOLOGY

List of Members

Chair Secretary, Past Chair Information Officer Finances Education Officer

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

Aims

1. Education regarding revisions of terms and organization of the epilepsies.

2. Translation of teaching slides / package into other languages

 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.

Commission Activities from July 2011 through July 2012

1) Business meeting AES 2012

A combined business meeting of the Commission and Task Force on Classification involved an eighthour working meeting to work on:

 a) the refinement of the new Organization of the Epilepsies with intense discussion on many aspects and the feedback received from the epilepsy community

b) the development of the Diagnostic Manual which was reviewed in prototype form Discussion focused on how the website will work in terms of videos, EEG, etc

c) the allocation of new syndromes to be developed by epileptologists, some of whom are not members of these bodies but who are experts in each syndrome.

The Diagnostic Manual is being developed with the addition of further syndromes, EEG and videos. This will require ongoing work to ensure it is a dynamic and updated tool for clinical use.

Project 1: Task Force on Classification, meeting at AES (with Commission)

See above – the Task Force was a major contributor to the Commission meeting as outlined above.

This Task Force has been committed to ensuring that the Diagnostic Manual will be an excellent resource.

Project 2: Task Force on Status Classification meeting in London

The Task Force met in London for five hours to work through the new Classification of the Status and in San Diego for three hours. A collaborative meeting was held in San Diego with the Epidemiology Task Force on Status and a mature document is being finalized.

Project 3: Development of Diagnostic Manual Website The Diagnostic Manual is now being directed by Dr Kate Riney and the website development is being performed by Prof Richard Sinnott, Director of e-Research at The University of Melbourne.

Recommendations for Future Work

Project 1: Task Force on Classification Objectives:

- 1) To develop the Diagnostic Manual further with the addition of new syndromes.
- To finalize the website for the Diagnostic Manual for global access.
- 3) To index videos, EEG samples, and brain images to interrelate with Diagnostic Manual on website.

Contribution towards meeting the Strategic Plan – Impact on the field of epilepsy care

- To improve education regarding epilepsy worldwide both with regard to diagnosis and syndrome classification
- To facilitate classification of epilepsies worldwide
- To enable research worldwide using consistent terminology
- To use these approaches as a basis for developing evidence-based syndromes and therefore improve treatment for people with epilepsy.

Outline of methodology and procedures

- To describe specific syndromes in the Diagnostic Manual
- To collect videos, EEG, images of MRI and index all features with the syndromes described on the website
- To extend this approach to less common syndromes.

Other partners or Commissions involved in the project (if any) and their role

- Pediatric Commission input integral and Chair Doug Nordli is part of this Task Force and the classification Commission.
- Genetics Commission Chair Sam Berkovic is member of our Commission.

Project timeline and expected milestones

 2013 – Diagnostic Manual to be made available globally. Further syndromes to be added. Videos

COMMISSION ON CLASSIFICATION AND TERMINOLOGY (continued)

and EEGs to be indexed with each syndrome. Input from epileptologists outside the Commission and Task Force.

Deliverables (e.g. tangible products)

2010 - controlled vocabulary in place

2011 – six common syndromes on ILAE website

2012 – additional syndromes included, videos and

EEGs to be indexed for each syndrome

2013 – finalizing of new syndromes added to the

Diagnostic Manual

Other information

Members: 11 (6 USA, 3 Europe/UK, 1 Australian, 1 New Zealand)

Project 2: Task Force on Status classification Objective:

To develop a broad classification of Status Epilepticus

Contribution towards meeting the Strategic Plan -Impact on the field of epilepsy care

- To facilitate classification of epilepsies worldwide
- To enable research worldwide to use consistent terminology.

Outline of methodology and procedures

To establish an understanding of the different types of Status Epilepticus and how these terms are used by different groups eg epidemiology

Other partners or Commissions involved in the project (if any) and their role

Epidemiology Commission – the new classification is the result of a collaboration between our Task Force and the Epidemiology Commission with representation from Drs Shinnar and Hesdorffer

Project timeline and milestones

2011 – develop an understanding of the types of Status Epilepticus and draft a formal classification of Status Epilepticus

2012 – refine classification of status 2013 – finalization of the new Classification of Status Epilepticus

Deliverables (e.g. tangible products. Please specify timetable)

2011 – develop a classification

2012 – disseminate for international consultation

2013 – complete status classification

Other information

Members: 8 (3 USA, 1 Australian, 4 UK/Europe)

Ingrid E Scheffer Chair

COMMISSION ON DIAGNOSTIC **METHODS**

Commission Members

Chair Fernando Cendes (Brazil) Past Chair William Davis Gaillard

(USA)

Secretary Translational Research

Matthias Koepp (UK) Ingmar Blümcke (Germany)

Educational Officer Information Officer Treasurer

Prassana Jayakar (USA) Bruce Hermann (USA) Friedrich G Woermann

(Germany) Member Catherine Chiron

(France)

Task Forces

1. Neurophysiology:

Chair Prassana Jayakar (USA) Past Chair Demetrios Velis (Holland) Herman Stefan (Germany) Secretary 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) Friedrich G Woermann (Germany) Secretary Catherine Chiron (France) Members

William Theodore (USA) Donald W Gross (Canada) Seung Bong Hong (Korea) Dennis Spencer (USA)

Masako Watanabe (Japan)

3. Neuropathology:

Ingmar Blümcke (Germany) Chair Secretary Roberto Spreafico (Italy) Eleonora Aronica (Holland) Members

Hajime Miyata (Japan) Andre Palmini (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:

Ingmar Blümcke (Germany) Eleonora Aronica (Holland) Guiliano Avanzini (Italy) Scott Baraban (USÀ) 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 (USÀ) William Harkness (UK) Philippe Kahane (France) Giorgio LoRusso (Italy) Joseph Loturco (USA) Gary Mathern (USA) Imad Najm (USA) Cigdem Ozkara (Turkey) Andre Palmini (Brazil) Charles Raybaud (Canada) Alfonso Represa (France) Steven Roper (USA Noriko Salamon (ÚSA)

Andreas Schulze-Bonhage (Germany)

Roberto Spreafico (Italy) Laura Tassi (Italy) Maria Thom (UK) Annamaria Vezanni (Italy)

Harry Vinters (USA)

Review of Past Activities (2009 – 2013)

Commission meetings were held during AES meetings each year, to report progress and organize future work in Task Forces.

Specific aims and achievements of our Task Forces were as follows:

Neuropathology Task Force

The goals of the Neuropathology Task Force were as follows:

- 1. To provide standardized classification systems and terminology use for the diagnostic evaluation of epilepsy-associated brain lesions (mTLE-HS, Tumors, MCDs/FCDs, vascular malformations, encephalitis).
- 2. To validate existing and upcoming consensus classification systems by a larger cohort of practicing general neuro-/pathologists.
- 3. To disseminate new and upcoming consensus classification systems proposed by the ILAE Task

COMMISSION ON DIAGNOSTIC METHODS (continued)

Force of Neuropathology among epilepsy and pathology communities.

4. To allow access for members of low or middle income countries to advanced diagnostic standards and teaching.

During the past presidency period, our focus was on the classification of Focal Cortical Dysplasias (FCDs) (see below) and Hippocampal Sclerosis (HS). We organized a first meeting in November 2010 in Amsterdam (with financial ILAE support) in order to discuss the roadmap for a first international consensus classification for Hippocampal Sclerosis. During this meeting, we reviewed previous classification systems (which are many), terminology issues (which were a major challenge) and the potential benefit to achieve international consensus (either for clinical use on outcome prediction and cognitive impairment as well as better patient stratification for research). We then decided to evaluate our proposal (classification of HS into three clinico-pathological subtypes) using the digital slide microscopy platform again. Meanwhile, we achieved four consecutive evaluation periods reviewing a total of 55 human surgical samples (en bloc specimens as well as anatomically less-well preserved tissues). Meetings for progress reports were held in San Antonio (AES 2010), Verona (Hippocampal Spring Meeting 2011), Rome (ILAE 2011), Baltimore (AES 2011) and London (ECE 2012). Data analysis showed a reliable classification of HS subtypes (Type 1 = classic/severe form; Type 2 = atypical CA1 sclerosis; Type 3 = atypical CA4 sclerosis), with very good kappa values for agreement of hippocampal subfield specific pathology patterns. A first draft of the HS classification proposal has been prepared after fruitful discussion at the London 2012 ECE meeting and currently circulates among our TF members. At the 2012 AES meeting in San Diego, we may achieve further agreement to finalize the written document. We aim to publish the first ILAE consensus classification of HS during the term of this presidency.

FCD Task Force

The FCD Task Force has completed its mission by publishing a first international consensus classification of FCD in 2011 (*Epilepsia* 2011; 52(1):158-74). Subsequent activities included the interand intra-observer agreement survey with engagement of 34 colleagues, either well or less experienced in diagnosing epilepsy surgery specimens. We successfully introduced a digital (virtual) slide microscopy platform. The study provided evidence for a better and more reliable application of the ILAE classification using histopathological tools, as compared to the previous Palmini classification (*Epilepsia* 2012; 53:1341-8).

Imaging Task Force

The goals for 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"

3. promote global education/training in neuroimaging for neurologists and radiologists.

Specifically, "evidence-based" guidelines for imaging infants and children with recent-onset epilepsy were published in *Epilepsia* 2009; 50(9):2147-53, and a commentary on diagnostic testing study guidelines and practice parameters in *Epilepsia* 2011; 52(9):1750-6.

During meetings in Boston (AES 2009) and Rome (ILAE 2011), we prepared for a three-day workshop in London from 27-29 September, 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, which were non-diagnostic or inconclusive on visual routine exploration. 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 web Neuroimaging courses offered by Eurepa, which included students from different parts of the world, including many with scholarships offered by ILAE.

Neurophysiology Task Force

The Neurophysiology Task Force members met at AES the past three years and in Rome [2011] 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 has been organized at the ILAE meeting in Montreal 2013.

Neuropsychology Task Force

We had the unique opportunity to combine our interests and mandate with a special international workshop entitled Neuropsychology in the Care of People with Epilepsy. The meeting was held in Toronto, Canada, on 3-6 November 2010, organized under the

COMMISSION ON DIAGNOSTIC METHODS (continued)

auspices of the journal *Epileptic Disorders*. Members from our ILAE 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. The six main topic areas were:

- Neuropsychological assessment: state of the field at present.
- 2. Use of neuropsychology to understand the impact of epilepsy and seizures.
- 3. Use of neuropsychology to understand pharmacological treatments.
- 4. The use of neuropsychology to understand surgical treatments.
- 5. Mood and cognitive impairment in epilepsy.
- Assessing cognition in epilepsy via electrophysiological and functional imaging techniques.

The overarching goal of the meeting was to summarize and advance evidence-based neuropsychological practice in the care of children and adults with epilepsy. Each speaker was asked to address two primary questions including, "what are the important evidenced-based outcomes and their implications for improving diagnosis and clinical care in epilepsy?" and "what remains to be determined through future research to advance treatment." On the basis of the presentations and subsequent discussions, the written summaries were to conclude with specific recommendations for advancing clinical care and research. The formal text was published in 2011 after which the specific recommendations, approximately 120 in all, were then edited, collated, and distributed to all the members of our Task Force who then rankordered the recommendations in order of importance.

The results have been received and analyzed and a written summary document containing the primary recommendations along with proposed action plans for addressing the primary recommendations is in the hands of the Task Force members for their final comments and suggestions. The final document will be completed and submitted by 1 January 2013.

Fernando Cendes Chair

COMMISSION ON EDUCATION

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)

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)

Task Force on e-Textbook

Editor

Shih Hui Lim (China) Solomon Moshé (USA) Emilio Perucca (Italy) Chong Tin Tan (Malaysia)

Li Kuo Tan

Mission and Aims

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

Commission Activities from July 2011 through July 2012

ILAE e-Textbook

Need assistance from ILAE staff to help coordinate communication between editors and authors and to assist with the upload to the website. With this assistance, we expect some Chapters to be uploaded by early 2013 and before Montreal.

Activities include:

- Development of the framework of website suitable for e-textbook
- Technical editing of 50 Chapters
- Technical work related to Spanish and Chinese version.

Recommendations for Future Work

Capture of lectures:

Objective: This is to capture some of the education sessions during the IEC in Montreal, and other workshops.

Activities included:

- Recording of three workshops each lasting two days
- Post-recording processing
- Travel and hotel of one conference.

Chong Tin Tan

Chair

COMMISSION ON EPIDEMIOLOGY

List of Members

Co-Chair Co-Chair Past Chair Treasurer Secretary

Educational Officer

Information Officer

Executive Committee Liaison

Dale C Hesdorffer (USA) Ettore Beghi (Italy) Allen Hauser (USA) Ley Sander (UK) Charles Newton (Kenya) Torbjorn Tomson (Sweden) Giancarlo Logroscino (Italy) Ding Ding (China) Marco Medina

(Honduras) David Thurman (USA)

Subcommission Members

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

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

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

Status Epilepticus Task Force: Shlomo Shinnar (Chair), Giancarlo Logroscino, Ingrid Scheffer, Ding Ding, Ed Dudek

Aims

- 1. Prevention of death in epilepsy. This topic is undertaken through a systematic review of death in epilepsy with a focus on preventable causes of death.
- 2. Creation of a document on guidelines for the conduct of epidemiological studies of epilepsy.
- 3. Two systematic reviews to describe and determine the scope of psychiatric and cognitive comorbidities in epilepsy.
- A systematic review to determine the burden of mortality in epilepsy and the potentially preventable causes of death.
- 5. Description of the definition of Status Epilepticus for use in epidemiological studies.

The Commission is focused on four areas important to the burden of epilepsy: mortality in epilepsy; comorbidity in epilepsy; reliability of different epilepsy classifications; and development of an epidemiological definition of Status Epilepticus. These issues overlap with one another and together describe a large proportion of the burden of epilepsy. Additionally, the Commission aims to provide a document for the international community that provides guidelines for the conduct of epidemiological studies in epilepsy. The Commission's Task Forces include: Comorbidity Task

Force, Mortality Task Force, Reliability Task Force, and Definition of Status Epilepticus Task Force.

Commission Activities from July 2011 through July 2012

Meetings were held for the Commission and each of its Task Forces to organize and discuss activities that led to the accomplishments described in number 3 below. Additional meetings were held at AES, and some teleconference and Skype calls were held to further discuss relevant issues.

Accomplishments (2009-2010)

- 1. Publication of manuscript on standard definitions, study designs, and instruments to improve the quality of epidemiological research on epilepsy and to facilitate comparison of the burden of epilepsy worldwide
- 2. Publication of manuscript on a combined analysis of risk factors for SUDEP.
- 3. Review of abstracts on mortality in epilepsy, selection of full papers for systematic review of mortality in epilepsy, creation of data abstraction form, set up of web-based data abstraction form with linking excel file, download and distribution of PDFs for review, and beginning of the data abstraction.
- 4. Review of abstracts on psychiatric and cognitive comorbidity in epilepsy, creation of questions for systematic review, literature search for articles, review of abstracts, selection of papers needing full review, creation of data abstraction form, creation of web-based data abstraction form with excel file link, downloading and distribution of PDFs.
- 5. For work on the reliability of different epilepsy classifications, 71 case reports were collected on pediatric and adult epilepsy. They were reformatted to present each case in three ways: phenomenology only; phenomenology plus neurological examination; phenomenology, neurological examination and tests (EEG, MRI, genetics). These were reviewed by epileptologists who entered data on three classification systems.
- The Commission's Task Force on Definition of Status Epilepticus merged with the Commission on Classification's parallel Task Force and worked together on a joint document.
- 7. Proposed a SUDEP symposium which was accepted for the Montreal meeting.

Recommendations for Future Work

Related to the current work:

- 1. Completion of the three systematic reviews.
- 2. Completion of the manuscript on reliability of seizure classifications. Also completion of a second reliability study done in Latin America.
- 3. Providing any needed assistance to the Latin American PAHO efforts.

Dale Hesdorffer Co-Chair

COMMISSION ON GENETICS OF EPILEPSY

Members

Chair Past Chair Sam Berkovic (Australia) Ruth Ottman (USA) Shinichi Hirose (Japan) Thomas Sander (Germany) Peter DeJonghe (Belgium) Nigel Tan (Singapore) Sanjay Sisodyia (UK) Dan Lowenstein (USA)

Marcello Kauffman (Árgentina)

Alica Goldman (USÀ) Carla Marini (Italy)

Commission Officers

Secretary Alica Goldman (USA)
Finances Shinichi Hirose (Japan)
Info Officer Nigel Tan (Singapore)
Education Marcello Kauffman (Argentina)

Executive 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 2011 through July 2012

Regular teleconferences to drive the initiatives. Effective formation of the ILAE Consortium on Complex Epilepsies. Development of a Commission report on SCN1A testing in epilepsies

Accomplishments from July 2011 through July 2012

Initiative 1: Facilitation of VIREPA courses on genetics for physicians
Input into Educational session on genetics at International meetings
Development of a Commission report on SCN1A testing in epilepsies

Initiative 2: Developing brochure on genetics of epilepsy for patients. "Road tested" on clinic patients in the U.S. Modifications are being made and the plans are to develop versions for wider use. Liaison with IBE regarding dissemination of information on genetics

Initiative 3: Successful formation of ILAE Consortium on Complex Epilepsies. Highly successful meeting in London in March 2012 which has cemented the Consortium and developed a work plan which has been carried out

Recommendations for Future Work

Completion of the initial work of the Consortium and potential expansion of its aims

Sam Berkovic Chair

COMMISSION ON NEUROBIOLOGY

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 Liaison to

Heidrun Potschka (Germany)

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)
Aristea Galanopoulou (USA)
Roustem Khazipov (France)
Merab Kokaia (Sweden)
Holger Lerche (Germany)
Matthew Walker (UK)

Subcommission 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)

Subcommission 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 of the Commission

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 Activities from July 2011 through July 2012

The Commission has been actively working on the preparation of the WONOEP 2013 workshop content and format which will concern "New Tools to Study Epilepsy." The Task Force on Translational Research helped co-author with the AES Task Force a first organizing framework for development of optimized preclinical research practices in response to need for higher quality of preclinical evidence. As a result, a multidisciplinary group of experts in epilepsy drug development, animal models, and human clinical AED trials has finalized a report entitled "Identification of new treatments for epilepsy: Issues in preclinical methodology" which has been published in *Epilepsia* (2012). A follow-on meeting and several publications are planned after the London, 2012 Task Force meeting which took place October 2012. The Commission had agreed to move forward on the

COMMISSION ON NEUROBIOLOGY (continued)

planning of a project entitled "From Professional Training in Neurobiology to Regional Research Funding," proposed by the Educational Task Force of the Neurobiology Commission and that will be launched with the Educational Commission. The Neurobiology Commission had identified one junior investigator network after the San Servolo 2011 course. The designated leader is located in a less developed country (Ethiopia). This research project was proposed as a new project for the Neurobiology Commission but the project was not selected by the Bill Gates Foundation or any other grant agency and has not been followed up.

Accomplishments from July 2011 through July 2012

The WONOEP workshop generated four review papers that were published in 2012 in *Epilepsia*. The Task Force on Translational Research helped co-author with the AES Task Force a first organizing framework for development of optimized preclinical research practices in response to the need for higher quality of preclinical evidence. As a result, a multidisciplinary group of experts in epilepsy drug development, animal models, and human clinical AED trials is finalizing a report entitled "Identification of new treatments for epilepsy: Issues in preclinical methodology" which was published in *Epilepsia* in 2012. A follow-on meeting of the Task Force took place in London, 2012 and the follow up will take place at AES where the future manuscripts will be discussed.

Recommendations for Future Work

The Neurobiology Commission recommends that it focus on two main goals:

- (1) Promote further collaboration between the Translational Task Force and the AES Basic Science Committee to elaborate further appropriate guidelines for the design of appropriate and uniform preclinical models aimed at the development of new therapeutic strategies for some epilepsy syndromes.
- (2) Support the project "From Professional Training in Neurobiology to Regional Research Funding," proposed by the Educational Task Force of the Neurobiology Commission that will be launched with the Educational Commission.

Astrid Nehlig and Jeff Noebels

COMMISSION ON NEUROPSYCHOBIOLOGY

List of Members

Co-Chair Co-Chair Andres Kanner (USA)
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 from July 2011 through July 2012

The Commission continued the project of promoting translation and validation of screening instruments for psychiatric disorders 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 currently available in validate versions in English, German, Italian, Spanish, Portuguese, Japanese and Korean.

The first VIREPA course on psychiatric comorbidities of epilepsies has been developed and is currently running. The course is organized 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 nonepileptic seizures or psychoses.

The Commission developed a pragmatic approach to treatment of psychiatric comorbidities in epilepsy. A special issue of *Epilepsia* is dedicated to this problem providing 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 antiepileptic drugs.

The Task Force on Intellectual Disabilities, in conjunction with the IBE, developed a web-based survey in order 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 is working to a specific document on diagnoses of PNES and their approach. The document will be soon available.

Accomplishments (2011-2012)

The NDDI-E translated and validated in seven languages; a position paper on AEDs and suicide published in *Epilepsia; Epilepsia* supplement dedicated to treatment of psychiatric disorders in adults with epilepsy; VIREPA course on psychiatric aspects of epilepsy

COMMISSION ON NEUROPSYCHOBIOLOGY (continued)

Recommendations for Future Work

Following projects need 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 child neuropsychiatry: four documents to be finalized
- Task Force on intellectual disabilities: one document to be finalized
- Task Force on psychogenic nonepileptic seizures: one document to be published

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.

Marco Mula Co-Chair

COMMISSION ON PEDIATRICS

List of Members

Co-Chair Co-Chair Doug Nordli (USA) Perrine Plouin (France) Patrick Van Bogaert (Belgium) Helen Cross (UK)

Kevin Staley (USA)

Jaime Carriroza (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 healthcare 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 from July 2011 through July 2012

1. Transition childhood-adulthood

J Carriroza did an impressive job in collaboration with an adult epileptologist, Dr Tania Rodriguez from Chile. The starting point was questionnaires to be completed by pediatric and adult neurologists at an epilepsy Congress in Latin America in 2010. A checklist of 10 points that have to be considered to transfer a patient from a pediatric to an adult epileptologist emerged. This checklist could be implemented in a short report to be published on the ILAE website and in the "Grey Matters" in *Epilepsia*. An article on Transition Guidelines on Epilepsy should be written and publicized.

2. Infancy guidelines

A first draft of a manuscript aimed to create evidence guidelines has been written. The final version should be available for the end of the year. However, the question of guidelines for first line treatment is pending as no data exist in the literature. It was decided to undertake a survey that will be sent to child neurologists, addressing the question of treatment of all seizure types in infancy. This could delay the final edition of the paper.

3. Workshop Summer 2011 (Consensus Guidelines on Standards for Epilepsy Surgery)

The Task Force, chaired by H Cross, had meetings last year in Florence, this year in Lyon, and again in London. The objectives of the Task Force for the next year are as follows: (1) To publish recommendations for diagnostic evaluations in the planning for epilepsy surgery in children. This work is in continuation with the guidelines published in 2006. (2) To publish a new classification for seizures outcome which should be more appropriate for children. (3) To publish follow-up data from the 2004 cohort, on seizure outcome already acquired.

Proposed objectives of the next term will be to propose guidelines for the evaluation of developmental outcome after surgery, propose recommendations for specific surgical techniques, and establish a severity scale for seizure evaluation.

Administrative support to sort the outcome data (seizure outcome from 776 patients) is required to enable preparation for publication. The E10000 would provide support to Dr Gary Mathern, so data can be cleaned and divided up to individuals of the Task Force to enable full publication.

4. San Servolo Summer School

The 10th International Course on Epilepsy, San Servolo was successfully held on 14-25 July 2012. The theme was "Management of seizures and epilepsies in neonates and infants." P Plouin and F Vigevano directed the course. Sixty-three students from 44 countries and 34 teachers took part. The program included classical teaching, case presentations done by both students and teachers, and group projects. The course was successful but evaluation questionnaires by the students have not yet been analyzed. The financial balance is positive (income: 157,875 Euros, expenses 140,532 Euros).

5. MRI Negative Project

The funding of \$5,000 allocated for 2012 has not been requested or utilized. The goal of the project was to determine the utility of diagnostic tests in localization of the ER. A pilot questionnaire revealed that a majority of centers currently utilize chronic invasive recordings in all MRI negative patients; only a few used it as a discretionary test. Likewise, the use of ECoG was also very variable with only a few centers using it for surgical planning.

The initial focus of the study is thus on evaluating the role of invasive EEG recordings.

Hypotheses: Successful surgery can be accomplished in some MRI negative cases without the use of extraoperative invasive EEG Inclusion criteria:

Resective surgery

COMMISSION ON PEDIATRICS (continued)

- MRI negative criteria. Flair sequence, 3T, close cuts/volumetric. Retrospective review
- Outcome data available with at least one year follow up.

A study using 10 index cases is underway. De-identified data on each patient is being analyzed by experts from three centers. They are provided with the general information on each patient. Based on the interpretation of non-invasive test data, a surgical diagram is generated defining the proposed resection. The same is done following invasive data analyses. The surgical diagrams are compared to the actual resections performed to determine the utility of invasive EEG recordings.

Doug Nordli and Perrine Plouin Co-Chairs

COMMISSION ON THERAPEUTIC **STRATEGIES**

List of Members

Co-Chair Steve Schachter (USA)

Co-Chair Bernhard Steinhoff (Germany)

Information

Officer Guenter Kramer (Switzerland) Carlos Acevedo (Chile) Secretary Treasurer Patrick Kwan (Hong Kong)

Education

Officer Jack Pellock (USA) Past Co-Chair Jackie French (USA) Past Co-Chair Gary Mathern (USÁ) 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). See North American Regional Commission report for membership

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 Otzuki, 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 certainly addressed by the chairs of the Commission.

Mission of the Commission

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.

Commission Activities from July 2011 through November 2012

Botanical WIKI

Extensive progress has been made in designing and launching WIKI on the ILAE website dedicated to research concerning botanicals for the treatment of epilepsy.

Tasks

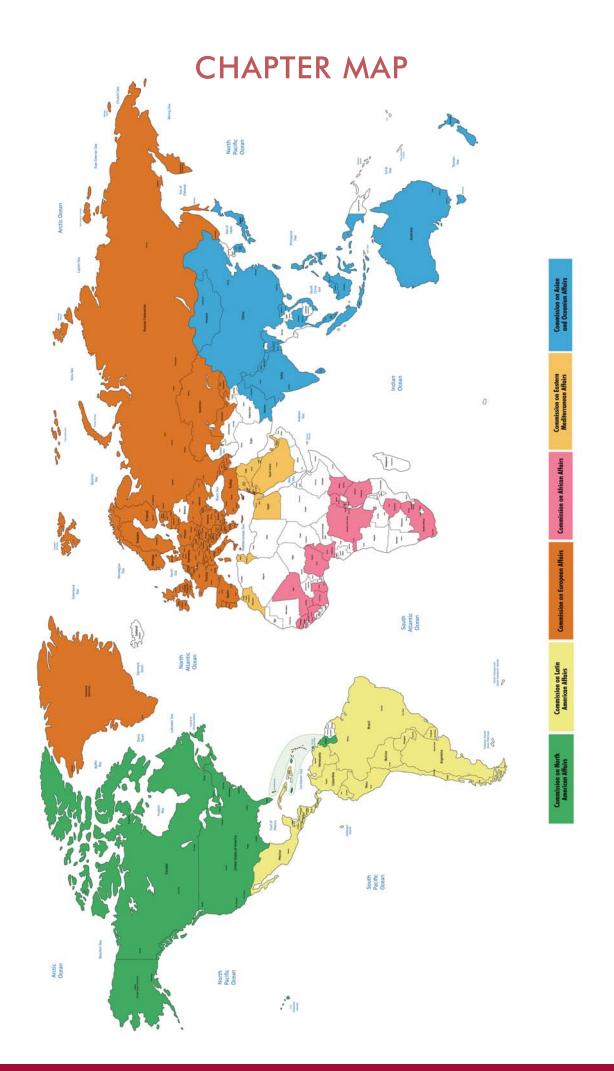
- Load pictures into WIKI
- Develop program to load approximately 750 entries into WIKI
- Develop a page for users to sign up for editing privileges to the WIKI
- Editing Privileges Extension for the WIKI

Task Force on Regulatory Harmonization

The Task Force on Regulatory Harmonization was originally scheduled to meet with EMA this year. The meeting did not occur, and plans are to schedule it for the coming year.

Steve Schachter and Bernard Steinhoff Co-Chairs





(Election dates are published for those Chapters that have provided them.)

Albanian League Against Epilepsy

President Jera Kruja Secretary-General Ali Kugo

Algerian League Against EpilepsyPresident Mahmoud Ait-Kaci-Ahmed

Amar Lebiod Secretary Saadi Ibrahim Treasurer

Argentinean League Against Epilepsy

President Roberto Caraballo Vice President Alfredo Thomson Secretary Nicolas Saris Julis Treasurer Veronica Campanille

Officer Election Date 24 January 2013

http://www.lace.org.ar

Armenian National League Against Epilepsy

President Gayane Melikyan 1st Vice President Biayna Soukhoudyan 2nd Vice President Tatyana Stepanyan Secretary-General Nune Yegiazaryan Irena Shadyan Treasurer

Epilepsy Society of Australia

Andrew Bleasel President Vice President Annie Bye Deepak Gill Secretary-General Treasurer Armin Mohamed

Officer Election Date November 2012

http://www.epilepsy-society.org.au

Austrian League Against Epilepsy

President Christoph Baumgartner 1st Secretary Susanne Pirker 2nd Secretary Eugen Trinka Martin Graf Treasurer 2nd Chairperson Barbara Plecko 3rd Chairperson Martha Feucht

December 2012 Officer Election Date http://www.ogfe.at/gesellschaft.htm

Azerbaijan League Against Epilepsy

President Sharif I Magalov Vice President Rena K Shiraliyeva Secretary-General Shahla Melikova Nailya N, Abbasova Treasurer

Officer Election Date June 2013

Bangladesh Epilepsy Foundation

President MA Mannan

Quazi Deen Mohammad 1st Vice President

2nd Vice President Anisul Haaque Muzharul Mannan Secretary-General Treasurer Shaheen Akhter

Belgian League Against Epilepsy

Patrick Van Bogaert President Vice President Paul Boon Secretary-General Eric Schmedding Treasurer Bernard Sadzot

http://www.ligueepilepsie.be http://www.epilepsieliga.be

Bolivian League Against Epilepsy

President Mario Camargo

1st Vice President Federico Fortun De La Quintana

2nd Vice President Rafael Prudencio Secretary-General Edil Escobar Mendoza

Wilma Jaldin Treasurer

Brazilian League Against Epilepsy

Luciano DePaola President

Past President Veriano Alexandre Junior Secretary-General Carlos Eduardo Soares Silvado

Treasurer Sergio Antoniuk

Maria Luiza G de Manreza Secretariat

http://www.epilepsia.org.br

Bulgarian Association Against Epilepsy

President Ivailo L Tournev Vice President Plamen S. Bojinov 2nd Vice President Stefan Tsekov Melania Radionova Secretary-General Ivan Litvinenko Treasurer

Cameroonian League Against Epilepsy

President Elie Mbonda 1st Vice President Alfred Njamnshi Kongnuy 2nd Vice President Jacques Narcisse Doumbe

Callixte Kuate Tegueu Secretary-General Samuel Elong Ngono Treasurer

Officer Election Date December 2013

Canadian League Against Epilepsy

President Sharon Whiting Past President Richard Wennberg Elizabeth Donner Treasurer

http://www.canadianepilepsy.org/

Chilean League Against Epilepsy

President Perla David Past President Juan Salinas Vice President Marcelo Devilat Secretary-General Eliana Jeldres Daniela Trivino Treasurer

(Election dates are published for those Chapters that have provided them.)

China Association Against Epilepsy

President Li Shichuo Wu Liwen Vice President Vice President Hong Zhen Treasurer Wu Jianzhong

Officer Election Date http://www.caae.org.cn Fourth Quarter 2014

Colombian League Against Epilepsy

President Orlando Carreño Past President Daniel Nariño

Secretary-General Angelica Maria Uscatequi

Costa Rica Chapter of the ILAE

President Franz Chaves Sell Vice President Dennis Chinchilla Weinstock Alexander Parajeles Secretary-General Rocio Quesada-Roman Secretary

Treasurer Roberto Brian Gago

Croatian League Against Epilepsy

Danilo Hodoba President Vice President Igor Prpic

Secretary-General Lierka Cvitanovic-Sojat

Treasurer Davor Sporis

Officer Election Date

http://www.ilae.hr

December 2012

Cuban League Against Epilepsy

Lilia Maria Morales Chacón President

www.epilepsiasocu.sld.cu

Epilepsy Society of Cyprus

President Savvas Papacostas Vice President Andriani Flourentzou Secretary-General Eleftherios Papathanasiou Marina Chryseliou Secretariat Treasurer Costas Michaelides

Officer Election Date 12 July 2012

Czech League Against Epilepsy

President Milan Brazdil Vice President Petr Marusic Secretary Roert Kuba Treasurer Miroslav Kalina

http://www.clpe.cz

Danish Epilepsy Society

President Anne Sabers Vice President Helle Hjalgrim

Secretary Hanne Mørk Christensen

Treasurer Poul Jennum

http://www.epilepsiselskabet.dk/

Dominican Republic League Against Epilepsy

President Diógenes Santos Viloria

Vice President José Silié Ruiz Secretary Milagros Gómez Treasurer Cristian López Diaz

Ecuadorian League Against Epilepsy

President Patricio Abad Vice President Isacc Yépez Secretary-General Beatriz Norvaez Treasurer Espinosa Sandra

Officer Election Date July 2013

Egyptian Society Against Epilepsy

Farouk Koura President Vice President Tarek Tawfik

Ahmed El-Ghonemy Secretary-General Mahmoud Allam Treasurer

Salvadorean League Against Epilepsy

(El Salvador)

Claudia Isabel Valencia President 1st Vice President Ricardo Alvarenga Quezada 2nd Vice President Ricardo Lungo Esquivel Secretary-General Mauricio Alfredo Muñoz Martinez Treasurer Mauricio Ernesto Palacios

Marchesini

Estonian League Against Epilepsy

Suley Haldre President

http://www.epilepsia.ee

Finnish Epilepsy Society

President Heikki Rantala Vice President Eija Gaily Leena Jutila Secretary-General Salla Lamusuo Treasurer

http://www.epilepsia.fi/epilepsiaseura

French League Against Epilepsy

Arnaud Biraben President Past President Alexis Arzimanoglou Laurent Vercueil Secretary-General Cécile Marchal Treasurer

http://www.lfce.fr/

Georgian Society Against Epilepsy

President Nana Tatishvilli Vice President Toidze Otar Sofia Kasradze Secretary-General Giroqi Japoridze Treasurer

(Election dates are published for those Chapters that have provided them.)

German League Against Epilepsy

President
Vice President
Secretary-General
2nd Secretary
Treasurer

Holger Lerche
Heinz Beck
Thomas Mayer
Hajo Hamer
Ulrich Bettendorf

http://www.dgfe.info

Epilepsy Society of Ghana

President Sammy Ohene 1st Vice President EV Badoe

2nd Vice President Augustina Charway Secretary-General AK Akpalu

Secretary-General AK Akpalu Treasurer Ben Ouave

Officer Election Date 2014

Greek League Against Epilepsy

President Athanasios Covanis
Vice President Kyriakos Garganis
Secretary-General Vasilis Kimiskidis

Treasurer Stylianos Giannakodimos

http://www.grlae.gr

Guatemala League Against Epilepsy

President Henry Stokes

Guinean League Against Epilepsy

President
1st Vice President
2nd Vice President
Secretary-General
Treasurer

Amara Cisse
Sélé Kourouma
Bah Fatoumata Binta
Alpha Laho Diallo
Mariam Barry

Honduran Epilepsy Society

President
Vice President
Past President
Secretary
Treasurer

Lazaro Molina
Roberto Padilla
Claudia Amador
Aleyda Rivera
Luis Cesar Rodriguez

Hong Kong Chapter of the ILAE

President Kwok-Leung Patrick Kwan
Past President Jason KY Fong

Secretary Colin Lui

Treasurer Mario Chak Wai Kwong

Hungarian Epilepsy League

President Jozsef Janszky
Past President Judit Jerney
President-Elect Andras Fogarasi
Secretary-General Zoltan Szupera
Treasurer Vera Juhos

Officer Election Date 2015

Indian Epilepsy Society

President Pravina Shah
Past President Satish Jain
Vice President P Satishchandra
Secretary-General Man Mehndiratta
Treasurer Manjari Tripathi

Officer Election Date April 2010 http://www.epilepsyindia.org

Indonesian Society Against Epilepsy

President Kurnia Kusumastuti
Past President Lina Soertidewi
Secretary-General Diah Kurnia Mirawati

Officer Election Date 2015

Iraqi Society Against Epilepsy

President Abdul Mutalib Abdul Kareem Vice President Ghaib Bashar Mohamed

Aliandeef

Treasurer Ali Kahdum Kareem

Officer Election Date March 2015

Irish Epilepsy League

President
Past President
Vice President
1st Vice President
2nd Vice President
Secretariat
Treasurer

Norman Delanty
Joseph McNenamin
Brian Sweeney
J. Morrow
Michael Hennessy
Mike Glynn
Bryan Lynch

Israeli Chapter of the ILAE

President Ilan Blatt Secretary/Treasurer Meir Bialer

Italian League Against Epilepsy

President Roberto Michelucci Secretary-General Giuseppe Capovilla

http://www.lice.it

Ivorian League (Cote D'Ivoire)

President
Vice President
Secretary-General
Treasurer
Organization Officer

Francois Akani
Berthe Assi
Evelyne Aka Diarra
Mariam Doumbia
Ange Kouame Assouan

(Election dates are published for those Chapters that have provided them.)

Jamaican League Against Epilepsy

President Amza Ali Vice President Robert Gray

Secretary-General Roxanne Melbourne Chambers

Treasurer Judy Tapper

Officer Election Date June 2013

http://www.jlae.org

Japan Epilepsy Society

President Sunao Kaneko Secretary-General Masako Watanabe Kiyotaka Hashizume Secretary

Officer Election Date October 2013 http://square.umin.ac.jp/jes/en/index.html

Jordanian Chapter of Epilepsy

Mohammed Al-Shehab President Vice President Ammar Mubaidin 2nd Vice President Majed Habahb Abdullah Younes Treasurer

Officer Election Date December 2013

Kazakhstan National League Against Epilepsy

President Roza Aldundarova Vice President Leila Dairbeveva

Kenya Society For Epilepsy

Paul G. Kioy President Max Okonji Past President Vice President Romi Grammaticas

Secretary-General E Amao Treasurer M Qureshi

Korean Epilepsy Society

President Heung Dong Kim 1st Vice President Song Ahm Lee 2nd Vice President Chun Kee Chung 3rs Vice President Kyoung Heo Secretary-General Hoon Chul Kang Treasurer Joon Soo Lee

Officer Election Date 19 March 2013

Association Against Epilepsy of Kosovo

Valbana Govori President 1st Vice President Nazim Dakaj 2nd Vice President Adurrahim Gerguri Secretary-General Mehdi Shehu Nexhat Shatri Treasurer

Officer Election Date 2011 **Kuwait League Against Epilepsy**

Abdulaziz Ashkanani President Raed Alroughani Secretary-General Treasurer Khalid Al-Hassan

Officer Election Date 5 March 2011

Kyrgyz League Against Epilepsy

President Arstanbek Murzaliev Secretary Asel Jusopova

Latvian League Against Epilepsy

Eglis Vitols President Secretary-General Lolita Budnika

Lebanese League Against Epilepsy

Wassim Nasreddine President Vice President Ghassan Hmeimess Secretary Sandra Sabbagh Treasurer Salim Atrouni

Society of Epileptologists of Lithuania

President Ruta Mameniskiene Past President Nerija Vaiciene-Magistris

Secretary-General Egle Navickiene

League Against Epilepsy of Republic Macedonia

Emilija Čvetkovska President Vice President Dijana Nikodijevic-Kedeva

1st Secretary Ana Doneva 2nd Secretary Merita Ismajli-Marku

Officer Election Date 2012

Malaysian Society of Neurosciences

President Raymond Azman Ali Sau Wei Wong Secretary-General Azmi Abdul Rashid Treasurer

Officer Election Date June 2012

http://www.neuro.org.my/

Malian League Against Epilepsy

Baba Koumare President 1st Vice President Karamoko Nimaga 2nd Vice President Karambe Mamadou Secretary-General Youssoufa Maiga Fatoumata Dicko Traore Treasurer

Officer Election Date July 2012

Epilepsy Society of Malta

President Anthony Galea Debono

Vice President Doriette Soler 2nd Vice President Norbert Vella Secretary-General Janet Mifsud Josanne Aquilina Treasurer

Officer Election Date 2012

(Election dates are published for those Chapters that have provided them.)

Mexican League Against Epilepsy

President Horacio Senties
Past President Eduardo Barragán

Secretary-General Ildefonso Rodriguez Leyva Treasurer Juan Carlos Resendiz Aparicio

Officer Election Date 17 September 2012

Moldavian League Against Epilepsy

President Stanislav Groppa Vice President Mihail Hotineanu Treasurer Dumitru Cernobrov

Mongolian Epilepsy Society

President G Tsagaankhuu Secretary-General A Tovuudorj

Officer Election Date 2014

Moroccan League Against Epilepsy

President
Vice President
Secretary-General
Treasurer

Hamid Ouhabi
Reda Ouazzani
Fettouma Moutawakkil
Saoudi Zemrag

Nepal Epilepsy Society

President Rabindra Shrestha
Past President Jagdish Prasad Agrawal
Vice President Saroj Prasad Ojha
Secretary-General Sudarshan Pradhan
Treasurer Pawan Kumar

Officer Election Date April 2012

Dutch League Against Epilepsy (Netherlands)

President
Past President
Secretary-General
Secretariat
Secretariat
Gerrit-Jan de Haan
Steven A J de Froe
Gerald Hageman
Odile van Iersel
G Thoonen

New Zealand League Against Epilepsy

President Peter Bergin
Vice President Lynette Sadleir
Secretary-General Elizabeth Walker
Treasurer Claire Spooner

http://www.epilepsy.org.nz/

Nicaragua Chapter of the ILAE

President Foad Hassan Morales
1st Vice President Walter Diaz
Secretary-General Luis Garcia

Treasurer Pablo Navarrete

Nigeria League Against Epilepsy

President Ikenna Ö Önwukewe Secretary Birnius Ezeala-Adikaibe Treasurer Oluchi S Ekenze

Officer Election Date 2014

Norwegian League Against Epilepsy

President Morten Lossius
Vice President Eylert Brodtkorb
Secretary Nina Benan
Treasurer Torliev Svendsen

Epilepsy Association of Pakistan

President Shaukat Ali Past President Hasan Aziz Secretary Zarine Mogal Treasurer Farah Minhas

Officer Election Date June 2012

Palestina League Against Epilepsy

President
1st Vice President
2nd Vice President
Secretary-General
Treasurer

Adel Misk
Zayed Afawi
Ziad Shqir
Hesam Amleh
May Mubarak

Panama League Against Epilepsy

President
Secretary-General
Secretariat
Treasurer

Luis Carlos Castillo
Evelia Gomez Wong
Ernesto Triana Bernal
Fernando Garcia

Paraguayan League Against Epilepsy

President Marta Cabrera de Abente-Arbo Past President Carlos Arbo Oze de Morvil

Vice President Nancy Monges
Secretary Alicia Aldana
Treasurer Luis Taboada

Peruvian League Against Epilepsy

President Alberto Díaz Vásquez
Past President Juan Altamirano del Pozo
Vice President Julio Espinoza Jimenez
Secretariat Patricia Campos Olazabal
Treasurer Daniel Koc Gonzáles

Philippine League Against Epilepsy, Inc.

President
Past President
1st Vice President
2nd Vice President
Secretary-General
Treasurer

Hazel Paragua
Josephine Gutierrez
Jean Marie B Ahorro
Fe Abacar De Los Reyes
Bernadette Terencio
Katerina Tanya P
Perez-Gosiengfiao

http://www.plae.org.ph/

(Election dates are published for those Chapters that have provided them.)

Polish Society of Epileptology

President Joanna Jedrzeiczak Vice President Ewa Motta

2nd Vice President Janusz Wendorff Secretary-General Albena Grabowska-Grzyb

Treasurer Maria Mazurkiewicz-Beldzinska

Officer Election Date 2014

http://www.epilepsy.pl/

Portuguese League Against Epilepsy

Francisco Sales President Vice President Ricardo Rego Treasurer João Chavez

http://www.epilepsia.pt/lpce

Qatar League Against Epilepsy

Hassan Al Hail President Vice President Boulenuar Mesraua Secretary-General Tag Eldin Sokrab Osama El Alamy Treasurer

Officer Election Date March 2013 http://gatarneuroscience.webs.com/

Romania Society Against Epilepsy

Ioan-Radu Rogozea President Vice President Al Serbanescu Claudia Portmann Secretary-General

Russian League Against Epilepsy

President Gagik Avakian Alla Guekht Secretary-General Treasurer Anna Lebedeva

Saudi Chapter of Epilepsy

Raidah Al Baradie President Past President Sonia A Khan 1st Vice President Suad Al Yamani 2nd Vice President Mohammed Jan 3rd Vice President Shireen Qureshi

4th Vice President Abdulrahman J Sabbagh Secretary-General Ahmed Al Rumayan Ali Al Ghatani

Treasurer

Officer Flection Date March 2013

Senegal League Against Epilepsy

Amadou Gallo Diop President 1st Vice President Lamine Gueve Secretary-General Moustapha Ndiave Treasurer Ndèye Fatou Ndoye

Singapore Epilepsy Society

Shih-Hui Lim President Vice President John Thomas Secretary Andrew Pan Treasurer Hian-Tat Ong

Slovak League Against Epilepsy

President Vladimir Donath Vice President Pavol Sykora

Slovenian League Against Epilepsy

President Matevz Krzan Igor M Ravnik Past President Vice President Bogdan Lorber Secretary-General Marko Korosec Secretary Svetana Simic

http://www.epilepsija.org/en/

Epilepsy Society of South Africa

President Roland Eastman Secretary-General James Butler J Wilmshurst Treasurer

Officer Election Date 15 March 2013

Spanish League Against Epilepsy

Gonzalo Alarcon President Past President Ines Picornell Darder Vice President Jose Maria Castilla Garrido Secretary Angel Ponce de Leon Paredes Fernando Carceller Benito Treasurer

Sri Lankan League Against Epilepsy

President Ranjanie Gamage President Elect Sunil Perera M T M Riffsy Vice President

1st Secretary Jithangi Wanigasinghe 2nd Secretary P D Rathnayake Sunethra Senanayake Treasurer

Swedish Epilepsy Society

President Eva Kumlien Vice President Kristina Källén Tove Hallböök Secretary-General Roland Flink Treasurer

Officer Election Date 9 November 2012 http://www.epilepsisallskapet.se/

Swiss League Against Epilepsy

President Günter Krämer Vice President Giovanni Foletti Secretary-General Daniela Erb Treasurer Christoph Pachlatko

Officer Election Date Spring 2013

CHAPTER DIRECTORY

(Election dates are published for those Chapters that have provided them.)

Syrian Chapter of Epilepsy

President Ahmad Khalifa
Vice President Anas Jawher
Secretary-General Sleie Abdulnaser
Treasurer Imad Eddin Sabbagh

Taiwan Epilepsy Society

President Wu Tony Secretary-General Lim Siew-Na Treasurer Elect Yen Der-Jen

Officer Election Date April 2013

Tanzania Epilepsy Association

President William BP Mutaja

Epilepsy Society of Thailand

President
Somchai Towanabut
Kanlaya Dhiravibulya
Secretary-General
Chacrin Na Banchang
Treasurer
Suwannee Pancharoen

Tunisian Association Against Epilepsy

President Chahnez Triki
Vice President Najoua Miladi
Secretary-General Mohamed Fredj
Treasurer Amina Gargouri

Turkish League Against Epilepsy

President
Vice President
Secretary-General
Treasurer

Boris Baklan
Candan G rses
Kadriye Agar Yildirim
Ibrahim ztura

Officer Election Date 2014 http://www.turkepilepsi.org.tr/

Epilepsy Society of Uganda

President Angelina Kakooza
Vice President David Basangwa
Secretary-General Augustine Mugarura
Treasurer Rebecca Wandeka

Officer Election Date February 2014

Ukrainian League Against Epilepsy

President Sergey M Kharchuk
Vice President Galina L Maryek
Secretariat Volodimir I Kharytonov
Treasurer George I Selyukov

Officer Election Date http://ulae-off.ucoz.net/

14 May 2011

Emirates League Against Epilepsy (UAE)

President
Vice President
Secretary-General
Treasurer

Tawfiq Al Saadi
Khaled Zamel
A. Rajarathinam
Ahmed Sameer

UK Chapter of the League (United Kingdom)

President Simon Shorvon
Secretary Yvonne M Hart
Treasurer John Duncan

http://www.ilae-uk.org.uk/

American Epilepsy Society (United States of America)

President Jacqueline French
Past President Frances Jensen
1st Vice President Elson So
2nd Vice President Amy Brooks-Kayal

2nd Vice President Amy Brooks-Kayo Treasurer Michael Privitera

December 2012

Officer Election Date http://www.aesnet.org

Uruguayan League Against Epilepsy

President Isabel Rega
Vice President Claudia Camejo
1st Secretary Esmerelda Borriano
2nd Secretary Patricia Braga
Treasurer Nury Sanchez

Officer Election Date 8 September 2012

Uzbekistan League Against Epilepsy

President
1st Vice President
2nd Vice President
Secretary-General
Treasurer

Yakuthon N Madjidova
Gulnora S Rakhimbaeva
Ibodulla A Kilichev
Khurshidakhon A Rasulova
Diana B Sattarova

Venezuelan League Against Epilepsy

President
Vice President
Secretary

Beatriz Gonzalez del Castillo
Brunilda Garcia de Parma
Beatriz H Guevara

Treasurer Jesus Silvera

http://www.livece.org/

Vietnam League Against Epilepsy

President
2nd Vice President
Secretary-General
1st Secretary
Tran Viet Nghi
Vu Anh Nhi
Le Quang Cuong
Ngo Ngoc Tan
Ta Thi Van Anh

Yugoslav Union of Leagues Against Epilepsy

President Nebojsa Jovic Secretary-General Mirjana Spasic

1st Secretary Ksenija Gebauer-Bukurov

2nd Secretary Nikola Vojvodic

Zimbabwe League Against Epilepsy

President G W Ngwende Secretary Jacob Mugumbate Treasurer Douglas Muzengi

LIGA ARGENTINA CONTRA LA EPILEPSIA (LACE)

Summary of Activities in 2011 and 2012

- We organized the Annual Meeting with special meeting subjects of: refractory epilepsy definition, new epilepsy and seizure classification and the ILAE/ANA guidelines about use of antiepileptic drugs. We were proud to have the participation of Dr Jacqueline French from the USA, and Drs Marilisa and Fernando Cendes, from Brazil
- We sponsored the Second Regional Latin American Congress that was held in Cordoba (Argentina) in April 2011. The Congress focused on epilepsy surgery
- In June 2011, along with the epilepsy group of the Argentinean Neurology Society, we organized the Second Legal and Social Epilepsy Implication Symposium, focused on epilepsy law, disability certification and drivers license in Argentina.

2012

- We organized our National Congress, 21-22 September. We were proud to have Drs Michael Duchowny, Angus Wilfong, and Kimford Meador from the USA participate
- LACE ILAE has provided three awards to the best three scientific works to participate in the last Epilepsy Congress in San Diego
- We sponsored a regional Latin American meeting that was held in Buenos Aires (Argentina) in June 2012, focused on epilepsy surgery
- We also have organized scientific activities in different provinces in Argentina.

Summary of Activities in Relation to Global Campaign in 2011 and 2012

We have also started to work in the epilepsy Latin American program, Strategic Plan on Epilepsy, together with PAHO and the Health Minister of Argentina. We are organizing an educational program on epilepsy to primary medical care providers in Argentina

Educational Activities

Different meetings on epilepsy in all Argentinian provinces and we prepared didactic material to doctors, nurses and general public on epilepsy

Activities in Conjunction with Local IBE Affiliate

Many social and scientific activities

Future Plans

- To organize our national congress: speakers P De Jonghe, G Cappovilla, P Veggiotti. Pre-congress meeting between LACE and LICE
- To continue working in the epilepsy Latin American program (Strategic Plan on Epilepsy) together with local PAHO and the Health Minister of Argentina.

Officer Election Date

24 January 2013

Report By

Roberto Caraballo, President

EPILEPSY SOCIETY OF AUSTRALIA

Meeting

Annual Scientific Meeting

Summary of Activities in 2011 and 2012

The Epilepsy Society of Australia conducts an Annual Scientific meeting in addition to other national meetings to improve and promote knowledge and research in the field of the epilepsies. Our Society works with the Joint Epilepsy Council of Australia in other endeavors to achieve these goals. The Society is the expert advisory body to the Australian and New Zealand Association of Neurologists.

Summary of Activities in Relation to Global Campaign in 2011 and 2012

Members of the Epilepsy Society of Australia (ESA) are active contributors to both the Commission on Asian and Oceanic Affairs (Drs Andrew Bleasel and John Dunne currently) and also to the Asian Epilepsy Academy (ASEPA) (Dr Wendyl D'Souza). Other members have contributed to the educational program of ASEPA, notably Dr Simon Harvey and Prof Ernest Somerville. The Timor epilepsy project run by Professor Somerville has been limited in recent times as a result of change in local conditions. The ESA makes an important contribution to the regional teaching of EEG and Epileptology. The ASEPA courses for both regularly include Australian faculty. We have held the small group tutorial format EEG course developed in Australia in Cochin, India; Bangkok, Thailand; and Penang, Malaysia, incorporating local faculty with great feedback.

Educational Activities

The Annual Scientific Meeting was held in Brisbane in 2011 and Hobart in 2012. Both meetings were well attended with approximately 200 attendees at each of these three-day meetings. Invited keynote speakers

were Prof Helen Cross – UK (2011), Prof Kevin Staley – USA (2012) and Prof Ennapadam Krishnamoorthy – India (2012). Each made marvelous contributions. These meetings featured presentations of the latest research regarding epilepsy from a number of Australian research centers. The annual EEG course conducted by the ESA for the Australian and New Zealand Association of Neurologists was held in both 2011 and 2012. Primarily attended by neurologists in training, the two-day course attracted both good attendance and feedback. For the first time in 2013, we have invited an overseas contributor Prof Greg Cascino, Mayo Clinic, USA, who in addition to local experts will enhance the course. Epilepsy Masterclass, a one-day meeting, is held annually with the target audience neurologists in training. Invited local experts and an interactive format ensured a high level of participation.

Activities in Conjunction with Local IBE Affiliate

Satellite meetings conducted by Joint Epilepsy Council of Australia (JECA) members (Epilepsy Queensland and Epilepsy Action Australia) were held with the Annual Scientific Meeting in Brisbane. Again a number of members of the ESA contributed to lectures and debates. At a state level smaller meetings of JECA meetings have also been supported. Currently both JECA and the ESA are fighting a government decision that would curtail the use of VNS.

Future Plans

The AGM November 2012 saw a new secretariat being appointed to the ESA: President Dr Dan McLaughlin, Vice-President Dr Cecilie Lander, Secretary Dr Kate Riney, Treasurer Dr Stephen Malone. The above activities are to continue annually with each requiring considerable organization to maintain the highest standard possible. An initiative to provide scholarships to neurologists within the Asian and Oceanic region for three-month attachments to epilepsy centers in Australia is being developed.

Officer Election Date

November 2012

Report By

Dr Dan McLaughlin

AZERBAIJAN LEAGUE AGAINST EPILEPSY

Publications

1. The Prevalence of Epilepsy in the Nakhichevan Autonomous Republic of Azerbaijan. Sharif I.

- Magalov, Nusrat F. Hasanov, Nargiz X. Azizova et al. CNS & Neurological Disorders Drug Targets, 11. 2012, p.102-109.
- Neuroendocrine disorders of epilepsy in women.
 S.I. Mahalov, N.A. Guluzadeh, M.R. Guliyev, Sh.N. Mehdiyeva. Ukrainian Journal of Clinical and Laboratory Medicine 2012, Vol.7, no 1,p.158-161.
- 3. Gender relations of patients with epilepsy in Azerbaijan. Sh.I. Magalov, D.M. Khalilova. *International Scientific-Practical Journal*, Neurology and Neurosurgery in Belarus, 3 (11), 2011, p.136-140

Meeting

- 1. Meeting devoted to the study of epilepsy in women.
- 2. Meeting devoted to the study of the epidemiology of epilepsy in regions of Azerbaijan.

Summary of Activities in 2011 and 2012

Studied the epidemiology of epilepsy in the Sharur district of Nakhichevan Autonomous Republic (population 114,451) of Azerbaijan and in Ganja City (population 336,100) of Azerbaijan; including the quality of life of patients with epilepsy; and epilepsy in women in the population Azerbaijan

Educational Activities

The 3rd Caucasian Regional Summer School on Clinical Epileptology was held in Baku, 16-21 October, 2011

Future Plans

Continuation of study of epilepsy in women in Azerbaijan

Officer Election Date

June 2013

Report By

President, Sharif Magalov and Secretary-General, Shahla Melikova

BELGIAN LEAGUE AGAINST EPILEPSY

Summary of Activities in 2011 and 2012

The Belgian League organized a national meeting on 18 June 2011 in La Hulpe. The main theme was Status Epilepticus. Prof Simon Shorvon gave the key lecture. The meeting was very successful. In addition to their usual information activities for patients and their families, both branches of the Belgian League had specific activities in 2011 and 2012. The "Ligue Francophone Belge contre l'épilepsie" had its Annual

Meeting on 16 June 2012. Prof François Mauguière gave the key lecture about insular epilepsy. The members of the League had frequent meetings during the past two years to create an interactive e-learning program on epilepsy dedicated to physicians in training. Six modules are now available online. The "Vlaamse Liga Tegen Epilepsie" organized on 11 February 2012 for the fifth Day of Epilepsy in Vilvoorde. A four and a half-day course was organized in 2012 for continuous training of pediatricians and neurologists.

Future Plans

For 2013, campaigns in the media and manifestations around the European Epilepsy Day will be organized.

Report By

Patrick Van Bogaert

CAMEROONIAN LEAGUE AGAINST EPILEPSY (CLAE)

Meeting

27 January 2011 (Yaoundé) and 10 February 2011 (Douala), 3 March 2012 (Douala)

Summary of Activities in 2011 and 2012

27 January 2011: Meeting of the General Assembly of the CLAE in Yaoundé at the Cameroon National Medical Council. Included was the election of Dr Jacques Doumbe, neurologist at the Douala Laquintinie Hospital as 2nd Vice President of the League to replace the late Dr Ndo Belinga. Dr Victor Sini, neurologist at the Yaoundé Central Hospital was also elected as Vice Chair of the Scientific Committee. Admission of new members: Dr Faustin Yepnio Njonda (last year neurology training at Limoges, France), Dr Francis Nnanga (specialist in internal medicine with neurology as option, Military Hospital Yaoundé) and Dr Godwin Tatah (last year training in internal medicine with neurology as option, France), Dr Joseph Fondop (neurosurgeon, Douala Laquintinie Hospital). Set up of two discussion groups, one in Douala (Chair: Dr Doumbe Jacques) and the other in Yaoundé (Chair: Prof Njamnshi) for the organization and implementation of the 2011 Action Plan.

10 February 2011 and 13 March 2011: Meeting at Douala for the elaboration of the 2011 Action Plan. Many propositions were made and sent to the Executive for further discussion, adoption and implementation.

28 August - 1 September 2011: International Epilepsy Congress, Rome, Italy. General Assembly of the ILAE:

final adoption of the candidature of Cameroon as a National Chapter of the ILAE. Our League was represented in this meeting by the President (Prof Elie Mbonda), the Secretary-General (Dr Callixte Kuate) and the Vice Chair of the Scientific Commission (Dr Victor Sini). Meeting of the ILAE Commission on African Affairs: The 2012 Action Plan of the African Commission was discussed and the budget adopted. Preparation of the 1st African Epilepsy Congress, Nairobi, Kenya

30 January to 2 February 2012, Marseille, France: Participation in the Congress of the French Society for Pediatric Neurology (Dr Séraphin Nguefack)

2 to 4 February 2012, Antebe, Uganda: participation in the International Congress on Pediatric Neurology (Prof Elie Mbonda)

3 March 2012, Douala, Cameroon: General Assembly of the CLAE

- Amendments of the constitution. An amendment was voted by 100 percent of 13 members present, on article six for the suppression of the mention "in charge of international relations" for the 1st Vice President and "in charge of national relations" for the 2nd Vice President.
- Admission of new members: New members have been admitted to the CLAE: Dr Kamdem Fokam Aimé (consultant neurologist, Bafoussam Regional Hospital), Dr Djouakep Noël (consultant pediatrician, Douala Laquintinie Hospital), Dr Ndensi Jean Paul (consultant pediatrician, Bafoussam EEC Hospital).
- 3. Adoption of the CLAE 2012 Action Plan. 5-6
 December 2012: Sensitization campaign and
 consultation of 103 patients with epilepsy in three
 health centers in economic capital Douala: District
 Hospital of Nylon, Bonassama District Hospital and
 Hôpital Saint Albert Legrand of Bonaberi.

Summary of Activities in Relation to Global Campaign in 2011 and 2012

15 September 2011: Dr Samuel Elong Ngono, Treasurer of the Cameroonian League has participated on a radio program on epilepsy in an international German radio Deutsche Welle. http://www.dwworld.de/dw/article/0,,6618001,00.html?maca=frapodcast sante-1858-xml-mrss

Educational Activities

May and June 2011: Activities in Mbam area, Centre Cameroon, under supervision of the Ministry of Public Health: sensitization campaign against epilepsy, recruitment of patients and organization of training session in the Mbam area

- 4 December 2012: Training session for 10 general practitioners at the District Hospital of Nylon. Subject for discussion was semiology of seizures (Dr Jacques Doumbe) and medical treatment of epilepsy (Dr Callixte Kuate)
- 4 December 2012: Training session for nurses and paramedics at the Bonassama District Hospital on Clinical diagnosis of seizures and treatment of Status Epilepticus (Dr Joseph Fondop)

Activities in Conjunction with Local IBE Affiliate

5-6 December 2012: Sensitization campaign and distribution of more than one thousand prospectus on definition, clinical sign, etiologies of epilepsy, and care for people with epilepsy. Elaboration of prospectus and posters in collaboration with Sanofi-Aventis for sensitization campaign of the CLAE

Future Plans

- 1. Choose a National Epilepsy Day.
- 2. Organize a sensitization campaign in elementary and primary schools in Douala and Yaoundé.
- Organization of a sensitization campaign in two national companies, and training of health personnel of these companies in the diagnosis and treatment of epilepsy.
- 4. Organize the 1st Cameroonian Epilepsy Congress.

Officer Election Date

Probably end of year 2013

Report By

Dr Callixte Kuate Tegueu, Secretary-General

CANADIAN LEAGUE AGAINST EPILEPSY

Publications

CLAE Connections

Meeting

October 2012, Calgary Alberta

Educational Activities

The CLAE Biennial Meeting was conducted in Calgary Alberta in October 2012. It was attended by 115 delegates from across Canada.

EPILEPTOLOGY SOCIETY OF CHILE-CHILEAN CHAPTER ILAE

Publications

Chilean Journal of Epilepsy

Meeting

Meeting on 8-9 June

Summary of Activities in 2011 and 2012

2011 Continuing Education Workshops held the second Saturday of each month

- 8 January: "Epilepsy and Language," Labor income, FLGO. Marcelo Díaz
- 12 March: "Neuroimaging in epilepsy."
 Dr Cecilia Okuma. (New member) "Advances
 Study Group refractory epilepsy."
 Dr Lucila Andrade
- 9 April: "Psycholinguistics ITPA test skills and their relationship to learning school." Working income, FLGO. Ana Maria Torres
- 7 May: "Epilepsy and tuberous sclerosis, case report and review of the indications surgical." Daniela Andrade and Dr Lucila Pennaroli
- 10 11 June: XI Conference on Epilepsy (New syndromes new treatments)
- 9 July: "Alternative epiléticas emergency, intravenous valproic acid." Work entry.
 Dr. Carolina Gallegos. "Status not convulsive and non-convulsive seizures in the intensive care units and intermediate Carlos Van Buren Hospital." Work income, Dr Andrea Aguirre
- 13 August: "Mesial temporal epilepsy: can characterize network-mesial temporal Octal EEG limbic surface" Dr Cayetano Napolitano. "Electrocroticografía intraoperative cortical dysplasias." Working admission, Dr Hernan Acevedo
- 10 September: "Aspects electroclinical in addressing neonatal seizures."
 Dr Daniela Pennaroli
- 15 October: "Epilepsy and Seizures in the Elderly" Dr Dario Ramirez
- 12 November: "Super Refractory Status: Clinical and electroencephalographic analysis of a case." Dr Cayetano Napolitano
- 14 December: Workshop #121 "Medial temporal Sclerosis in children: Clinical and Management" Dr Daniela Aguilera

This year is our sixth Colloquia in epilepsy. This continuing education activity takes place at the headquarters of the Society every Wednesday starting 5 October and ending on 30 November presented by Dr Perla David. The annual course is currently

sponsored by the University of Chile and by Recalcine for snacks offered to attendees. The program was developed by neurologists and psychiatrists belonging to our Society. Topics posted contribute to improving general medical and neurology fellows. Evaluation as in previous years has been positive. Plans are to continue it, renewing and modifying themes facilitate attendance times.

XII Winter Days of Epilepsy 2012 took place 9-10 June 2012, in the Hotel Neruda. The XII Winter Days of Epilepsy was entitled "Psychiatry in Epilepsy"

3-6 October 2012, we hosted the XXX Congress of the Society of Psychiatry and Neurology for Children and Adolescents (SOPNIA) in the city of Puerto Varas

The Chilean Journal of Epilepsy is the official publication of the Society. Dr Perla David is editor. This year we are publishing the 10th volume of this journal. It will present original papers, case reports, review papers and updates. It is currently in application process and achieved Scielo sponsorship. The journal is also online on its own website www.revistachilenadeepilepsia.cl. We are happy to announce that Dr Ledia Troncoso, has joined the editorial board of the journal.

Our website, www.epilepsiadechile.com, is available to members and the general public. It has information on the Society as well as the following sections:

1) Directory; 2) Partners; 3) Congress (Epilepsy Winter Days); 4) References (citations epilepsy); 5) Publications (Revista Chilena de Epilepsy and Standards); 6) Photo Gallery; 7) Tribune to physician; 8) the patients Tribune; 9) Links to ILAE, IBE, WHO and MINSAL; and 10) Latin American Epilepsy Day. The website has played an important role for college students, the most frequent users, and for references and contact information in addition to the contribution to various patients through their families.

The Society maintains contacts with the Society of Neurology, Psychiatry and Neurosurgery, the Society of Psychiatry and Neurology for Children and Adolescents, the Chilean Society of Pediatrics and the Association of Leagues Against Epilepsy of Chile (ANLICHE). Society members have participated in the normative group Epilepsy, the Ministry of Health of Chile. Also, members of our organization participated in the XXVIII Annual Congress SOPNIA in Epilepsy Symposium, one of the best evaluated activities of Congress 2009. The symposium was coordinated by Dra Perla David with the participation of Drs Marcelo Devilat, Ledia Troncoso, Jorge Förster and Tomas Mesa as well as the members of Chilean Society Epilepsy and Anliliche And Sopnia Infant Chilean Consensus.

The Society is a member of the Committee on Latin American Affairs of the International League Against Epilepsy. We were involved in the organization of the V Latin American Epilepsy Congress which was held in Nairobi from 5-8 November. Dr Marcelo Devilat, attended as a delegate representing our Society. Society members were invited to present lectures and six exhibited posters with Chilean research.

On 9 September, American Day Celebration of Epilepsy was celebrated in Latin American Epilepsy. One of the events that celebrate this occasion is organized by the Chilean League Against Epilepsy which was attended by Perla David, MD, President of the Society, along with ministry officials and hosts. The day of 12 September, was the commemoration of the Latin American Epilepsy Day.

The year 2012 welcomed the following new members: Dr Juan Luis Moya (April) and Dr Cristiane Zulic (July).

The library, located at the headquarters of the Society, receives the magazine edition of *Epilepsy* and *Epilepsy Chilean Journal*, and other publications that are available to members.

We remind you that the Board is getting the background of the partners for the accreditation of Epileptology Society of Chile, according to their participation in activities of the Society, in books and scientific journals, international and electronic.

Summary of Activities in Relation to Global Campaign in 2011 and 2012

Latinamerican Epilepsy Day celebration

Educational Activities

- Family social support
- APADENE Latinamerican Epilepsy Day celebration
- Pediatric Neurology Book 2012 Ed Mediterráneo Chilean Journal of Epilepsy 2011-2012 two volumes and Other Sleep Medicine.

Activities in Conjunction with Local IBE Affiliate

- Latinamerican epilepsy day celebration
- Pediatric Neurology Book 2012, Ed Mediterráneo Chilean Journal of Epilepsy 2011-2012, two volumes and Other Sleep Medicine

Future Plans

On 7 and 8 June 2013, there will be the XIII Winter Epilepsy, titled: "The Clinical and EEG as treatment guidelines." The Organizing Committee invites you to engage stakeholders through original works, which can

be sent to the website of the Society of Epileptology of Chile. Perla David, MD.

The Clinical Neurophysiology Society will have its X Conference on 10 November 2013 at the Davila Clinic Auditorium.

The Society of Neurology, Psychiatry and Neurosurgery (SONEPSYN) will hold its Congress LXVII 1-4 December 2013, in the city of Valdivia.

Officer Election Date

2012

Report By

Perla David, MD

CHINA ASSOCIATION AGAINST EPILEPSY (CAAE)

Publications

The Consensus on Using AEDs After Cranio-cerebral Operation (10th ECE)

Meeting

Meeting of standing members of CAAE Board, 11 February and 19 August 2012

Summary of Activities in 2011 and 2012

- 1. Celebrating the 5th and 6th International Epilepsy Caring Day (IECD) 28 June, the theme is "Follow Guidelines, Say No to False Advertisements" and "Stand up for Epilepsy" respectively. The activities included public education activities in most provinces in China, voluntary diagnosis/treatment, multi-mass media publicity, etc.
- 2. The 4th CAAE China International Epilepsy Forum (CIEF) was held in Nanjing, Jiangsu Province in September 2011; and the 3rd National Conference of EEG and Neurophysiology was held in Changsha, Hunan Province in May 2012.
- 3. The ASEPA-ASNA EEG Certification Examination (Second round, Part I & II) was conducted. Results are generally satisfactory.
- 4. A training course for EEG technicians via the Internet has been conducted successfully, 143 EEG technicians and doctors joined in.
- 5. The provincial epilepsy associations increased to 14.
- 6. A national survey on the organizations, personnel, working load and surgery of epilepsy in China was conducted in 2012.

Summary of Activities in Relation to Global

Campaign in 2011 and 2012

Continuing implementation of the Project "Epilepsy Prevention and Control Management in Rural China" in 135 counties in 18 provinces, covering 75 million people. Currently 83,518 people with epilepsy (PWE) are under free treatment with phenobarbital and 8,695 with valproic acid. The funding from the central government to this project was 13 million CHY (2.1 US million) annually.

Educational Activities

- Six training courses in collaboration with ASEPA were conducted in China in 2011-12.
- 2. A training course for EEG technicians via the Internet has been conducted successfully, 143 EEG technician and doctors joined in.
- 3. Clinical Epileptology Summer School held annually.

Activities in Conjunction with Local IBE Affiliate

- A special Committee of the CAAE concerning the IBE function, headed by Prof Hong Zhen, CAAE Vice president, has been set up to organize/coordinate patient activities
- Two PWE Activity Centers were set up in Beijing and Shanghai, respectively.

Future Plans

- 1. 5th CAAE China International Epilepsy Forum (CIEF) is planned for 12-15 September 2013 in Chongging Municipality.
- 2. A national examination of EEG technicians will be conducted in April 2013 in collaboration with the National Examination Center of the MOH.
- 3. ASEPA-ASNA EEG Certification Examination (Part II) will be conducted in May 2013.
- 4. Three ASEPA training courses will be held in 2013.
- 5. Three official documents concerning the criteria of epilepsy centers, regulations for epilepsy surgery administration and operation are hopefully issued by MOH in 2013.

Officer Election Date

Fourth quarter 2014

Report By

Shichuo Li, President

COSTA RICA CHAPTER

Summary of Activities in 2011 and 2012

Donation of computer equipment on behalf of Asociacion de Medicos de la Clinica Blibica to the EEG monitoring unit of San Juan de Dios hospital

Educational Activities

To encourage neurology residents and young neurologist to participate in LASE, VIREPA and other medical education courses in epilepsy

Future Plans

Building membership and adding integrated working groups for specific projects

Report By

Rocio Quesada Roman, MD

CROATIAN LEAGUE AGAINST EPILEPSY

Summary of Activities in 2011 and 2012 2011

- Celebration of Purple Day (The Epilepsy Day in Croatia, 14 February) in the Kaptol Center – organized by UHC Sestre milosrdnice, Croatian Child Neurology Society and the City Hall
- 9th EPNS Cavtat, Croatian Child Neurology Society, Cavtat-Dubrovnik, 11-14 May 2011
- 40th Symposium of Croatian Child Neurology Society, Cavtat, May 2011
- First International School Of Epilepsies And Movement Disorders, Dubrovnik, 12-16 May 2011
- Department of Neurology, UH Dubrava Summer Camp for Children with epilepsy, held in Selce, 2011
- Symposium of epilepsy, epileptic syndromes and EEG. Department of Pediatrics, UHC Split, 8-9 April 2011.

2012

- Celebration of Purple Day (The Epilepsy Day in Croatia) 11 February 2012 in the Kaptol Center – organized by UHC Sestre milosrdnice, Croatian Child Neurology Society and the City Hall
- Public lectures in the city of Zagreb, on 14
 February, Kaptol 27, organized by UHC Sestre milosrdnice and the City Hall, title: "Contemporary epilepsy therapy"
- "Epilepsy and encephalography" Course, Medical School Zagreb, Department of Neurology, UHC

- "Sestre milosrdnice" 16-27 April 2012
- The 10th Croatian Symposium on Epilepsy with international participation, Croatian League Against Epilepsy, the city of Opatija, Croatia, 27-30 June 2012, with the election of new leadership of CLAF
- Adriatic Neurology Forum, Dubrovnik, organized by UH Dubrava, Department of Neurology, 29 March - 1 April 2012
- Adriatic Summer Epilepsy School, International Epilepsy Teaching Course, under the auspices of University Hospital Zagreb and University Hospital Erlangen, June 2012, held on Island of Sipan, Dubrovnik, Croatia
- "Controversies in neurology," organized by the Department of Neurology, UHC Zagreb, Rebro, September 2012, held in Primosten, Croatia
- Symposium of Croatian Child Neurology Society with international participation, The election of new President and the Board Members of Croatian Child Neurology Society, held in HLZ, Zagreb, 8 December 2012. The CLAE elected the following leaders for the next four years: President is Prof Davor Sporis; General Secretary is Romana Gjergja Juraski, PhD, MD; and Treasurer is Jelena Bosnjak. We would like to thank the former President, Danilo Hodoba, PhD,MD and former Secretary-General Prof Ljerka Cvitanovic-Sojat for their efforts and dedication to the CLAE during the previous eight years. The members of the CLAE have been actively participating in international Congresses and meetings in the field of epileptology and published in international scientific journals.

Future Plans

We have plans to further promote epilepsy awareness, to connect with local and international organizations dedicated to health promotion and education in the field of epileptology. We would like to increase the number of specialists, educated in the field of epileptology and educated EEG technicians.

Officer Election Date

December 2012

THE CYPRUS CLINICAL

NEUROPHYSIOLOGY SOCIETY

Summary of Activities in 2011 and 2012

11 December 2012: The Cyprus Clinical Neurophysiology Society (CCNS) became a member of the IFCN

- 12 December 2012: All potential members are informed of the above great event, at the moment numbering 25 in total, including both Greek and Turkish Cypriots
- 14 December 2012: Interest is shown in the meeting "Horizons in Clinical Neurophysiology," to be held in Oxford in 2013, as it is being regarded as a European Chapter meeting
- 14 December 2012: The announcement in relation to the meeting "Horizons in Clinical Neurophysiology" is sent to all potential members of the CCNS
- 18 December 2012: The profile of the CCNS is updated on the IFCN website
- 27 December 2012: Holiday Greetings from the IFCN is sent to all potential members of the CCNS

Future Plans

A meeting of the CCNS Executive Committee will take place on 17 January 2013 to discuss future activities. This will include legalizing the CCNS within the Cyprus Republic, and ideas for educational activities within Cyprus.

Officer Election Date

12 July 2012

Report By

Eleftherios S. Papathanasiou, PhD

ECUADORIAN LEAGUE AGAINST EPILEPSY

Publications

Poster and journal articles presented and published

Meeting

Near on July National Neurology and Epilepsy Congress to be held in Quito

Summary of Activities in 2011 and 2012

- Continuous Medical Education activities: Have done six courses online (two in 2011 and four in 2012) with 500 attendees. Activities supported by pharmaceutical industry and Universidad de las Américas – UDLA, Hospital Metropolitano and Neurovida Neurology Center.
- 2. Successful organization of the VII LACE Quito 14 17 November, near to 800 inscriptions.
- OPS/OMS Initiative: National Epilepsy Program presented to the MSP authorities. Waiting for scheduled meetings and initiate activities focused on Primary Care on Epilepsy and Continuous Medical Education.

Educational Activities

Continuous Medical Education activities: Have done six courses online (two in 2011 and four in 2012) with 500 attendees. Activities supported by pharmaceutical industry and Universidad de las Américas – UDLA, Metropolitan Hospital and Neurovida

Future Plans

Executing the National Epilepsy Program presented to the MSP authorities focused on Primary Care on Epilepsy and Continuous Medical Education

Officer Election Date

July 2013

Report By

Patricio Abad Herrera

THE FINNISH EPILEPSY SOCIETY

Summary of Activities in 2011 and 2012

The Annual Meetings were held 24 March 2011 and 23 March 2012, both in Kuopio. Altogether 48 new members were accepted in 2011 and 2012. Members of the Finnish Epilepsy Society participate in the program that prepares and updates the national treatment guidelines. The updated treatment guidelines for children and adults with epilepsy will be published in early 2013. The Finnish Epilepsy Society works in collaboration with the Finnish Epilepsy Research Foundation. Members of the Executive Board participate in, as well as nominate professionals to, the grant evaluation board. In 2012 the Finnish Epilepsy Society participated in the founding of the Finnish Brain Council together with eight different national patient organizations and ten national scientific organizations. The Finnish Brain Council is a national organization related to European Brain Council.

Educational Activities

Two different national educational meetings were arranged each year. Educational topics included epilepsy as part of life, diversity of epilepsy, acute seizures and Status Epilepticus, as well as diagnosis and differential diagnosis of epilepsy. Invited foreign speakers were Prof Simon Shorvon (University College London, UK), Prof Kristl Vonc (University of Ghent, Belgium) and Dr John Paul Leach (Southern General Hospital, Glasgow, UK). Lectures were targeted to variety of professionals who treat patients with epilepsy. There have been between 90 and 190 attendants in each national meeting. The latest national educational meeting in Helsinki, 22-23 November 2012 celebrated the 20-year anniversary of the Finnish Epilepsy Society. Additionally several regional educational meetings took place each year. These were arranged in coordination with the Finnish Epilepsy Society, different University / Central Hospitals and sponsors. Lectures were targeted to different professionals who treat people with epilepsy. Topics and speakers were individually chosen to fulfill local educational needs.

Activities in Conjunction with Local IBE Affiliate

The Finnish Epilepsy Society works closely with the Finnish Epilepsy Association. Educational activities or other meetings for both people with epilepsy and professionals are arranged together on a yearly basis. The Finnish Epilepsy Society and the Finnish Epilepsy Association also have common Internet pages (www.epilepsia.fi). Activities for the European Epilepsy day are arranged together each year. In 2011 professor Asla Pitkänen received the Ambassador for Epilepsy Award after a joint nomination by the Finnish Epilepsy Society and the Finnish Epilepsy Association. In 2011 the EU Written Declaration on Epilepsy was promoted together.

Future Plans

Two national educational meetings and several regional educational meetings will be arranged during the next year. Activities will be planned in close co-operation with the Finnish Epilepsy Association.

Report By

Dr Leena Jutila, Secretary General

EPILEPSY SOCIETY OF GHANA

Summary of Activities in 2011 and 2012

- The WHO in partnership with ILAE and IBE is supporting Ghana in a four-year Fight Against Epilepsy initiative. The goal of the initiative is to improve access to care and services for people with epilepsy. The specific objectives are:
 - 1. To develop and engage in the strategy for

- delivering epilepsy care
- 2. To promote training of all professional healthcare providers, making them competent in diagnosing and treating epilepsy
- 3. To improve awareness of community groups to decrease stigma and increase demand for epilepsy care
- 4. To integrate provision of care and services for epilepsy within the primary healthcare system
- 5. To monitor and evaluate the project and disseminate new ideas and knowledge
- Continuing medical education for doctors, nurses
- Media programs national television morning show appearance on Stigma, First Aid and Living with Epilepsy, also on the Standpoint. A patient living with epilepsy was hosted with her husband and healthcare provider on the above.
- National launch of Fight Against Epilepsy Ghana Initiative

Summary of Activities in Relation to Global Campaign in 2011 and 2012

Fight Against Epilepsy Initiative WHO/Ghana Ministry of Health Initiative within WHO mhGAP framework. Partners: International League Against Epilepsy (ILAE) and International Bureau for Epilepsy (IBE)

Educational Activities

- Continuing medical education for doctors, community psychiatric nurses and medical assistants on management of epilepsy
- TV and radio appearances on Stigma, and First Aid
- Public educational awareness creation and advocacy material printed and distributed.

Future Plans

The National Coordinating Committee (NCC) has planned the following activities and budget for January to December 2013 based on the objectives. The Fight Against Epilepsy Initiative for 2013 will add on more implementation sites; one district each from the Volta and Central Regions of Ghana, and an additional district from the Northern Region, conduct refresher trainings and strengthen monitoring and supervision activities

Officer Election Date 2014

Report By

Dr Albert Akpalu, Secretary

GUATEMALA LEAGUE AGAINST EPILEPSY

Special Activities Year 2012

- 1. First Session of the programming of the activities of the whole year 2012.
- 2. Approval of the year 2012 Plan.
- 3. First Scientific activity on basic and academia aspects of epilepsy.
- 4. Organization of 15 subchapters of the Chapter Guatemala International League Against Epilepsy.
- General programming of the yearly activities of each subchapter of ILAE.
- 6. Manufacturing of the educational materials for patients with epilepsy.
- 7. Manufacturing of educational materials for patients and their families.
- 8. Manufacturing of educational materials for school teachers and students.
- 9. Creation of video materials for patients, relatives, teachers and general practitioners.
- 10. Production of audio material for patient and physician education on epilepsy.
- 11. Production of video material for the general public about epilepsy.
- 12. Special planning for activities for elementary school teachers, materials about epilepsy.
- 13. Inauguration in all the subchapters in Guatemala in different status or departments of specialized clinics for the attention of patients with epilepsy.
- 14. Special training courses about epilepsy diagnosis and management of neurology residents in the areas of Pediatric Neurology, Adult Neurology and Clinical Neurophysiology, these activities with the support of State University of San Carlos de Guatemala.
- 15. Monthly activities in the subchapters and in the headquarters of the League, scientific meetings with specialists in the neurological branches covering different aspects in the management, treatment and research in epilepsy.
- 16. Monthly joint meeting with the neurological associations and epilepsy organizations with the support of the Continuum of the World Federation of Neurology, discussing epilepsy and other related topics of the neurological sciences.
- 17. Monthly meeting of the Commission of Continuous Medical Education of the College of Physicians of Guatemala, presenting to all the organized medical community of Guatemala in topics of epilepsy management and guidelines in epilepsy for the physicians that are not neurologists.
- 18. We participated in electronic teaching courses for physicians throughout the country via the Internet and through our web page. This was organized and presented through the web page: www.Neurologia para todos.com.
- 19. Participate in courses given on our web page about

- epilepsy topics and increase awareness about the prevalence, incidence and importance of the correct management of the epilepsies.
- 20. At monthly intervals, members of the League and the Bureau deliver lectures about epilepsy and related basic neuroscience topics in the subchapters spread all over the country of Guatemala.
- 21. Active participation in research projects about social, academic and clinical aspects of epilepsy in different areas of interest.
- 22. Participation in courses for neurological residents and other professionals interested in electrophysiology specially supporting knowledge in interpreting Electrodiagnostic tests in the field of the Neurosciences.
- 23. Jointly with the Neurology and Neurophysiology Residency programs of the University of San Carlos participating in a joint effort for developing protocols for treatment and management of epilepsy.
- 24. Direct participation through the neurology residency program and the university in educational courses on epilepsy at postgraduate and undergraduate levels at the University of San Carlos of Guatemala
- 25. Our organizations are deeply involved in the development of the epilepsy surgery programs in Guatemala.
- 26. Joint participation with the School of Psychology of The University of San Carlos in the development and support in the area of neuropsychology in epilepsy.
- 27. Planning of the monthly activities about epilepsy for the general population that are not medical physicians.
- 28. In the subchapter of Coban Alta Verapaz, 250 kms from Guatemala city, the local Committee, with the help of the city government and local organizations is involved in the construction of a multi-clinic facility with practical and modern facilities. It is expected to be a pioneer Project in Guatemala and Central America, and should be completed in 2013.
- 29. With the Guatemala Red Cross we have an agreement of mutual cooperation for joint projects in the field of Epilepsy and Neurological diseases. The organizations involved are Chapter Guatemala ILAE, Chapter Guatemala and IBE, and neurology training program of the University of San Carlos of Guatemala. Among the present activities the League runs an epilepsy clinic in the headquarters of the Red Cross and the Neurology residency program provides a medical Neurology Resident. The Red Cross provides the facilities and modern equipment of Brain Mapping and EEG, and also supplies paramedical personnel.

- 30. The Red Cross has this year purchased the first class equipment for Brain Mapping and EEG.
- 31. A cooperation agreement has been signed between the Chapter Guatemala, International League Against Epilepsy, the International Bureau for Epilepsy, The Neurology-Clinical Neurophysiology Residency programs of the University of San Carlos, and the Guatemala Red Cross. The main objective is to pursue an integral concept of health: Health is not just the absence of disease but a complete sense of well being socially, medically and economically.
- 32. Guatemala is a multilingual, multicultural society. Twenty-one languages are spoken in addition to the official language Spanish and less than half of the population read and write. A very innovative process was started with Dr Henry B Stokes who for the first time in the country made a set of audio CDs in 10 different languages with the help of local communities. This material is instrumental for teaching epilepsy to many rural communities in their own languages. A large number of CDs were produced and distributed with a special grant of U. S. \$5,000 that was awarded by the IBE International Bureau for Epilepsy. A second phase of this process is being implemented for the near future. This is also a joint venture between IBE, and ILAE national Chapters.
- 33. Meetings: Each year for the last 25 years the Chapter Guatemala of ILAE and the Chapter Guatemala IBE and the Guatemalan Association of Neurological Sciences organizes with its fellow Societies from Spain, the Iberocentroamerican Congreso of Neurological Sciences and Epilepsy with the participation of professionals from Central America, Latin America, USA, and Europe.
- 34. Local organizations of the Subchapters all over the country are made up of: physicians, teachers, prominent members of the community, social workers, patients and relatives of patients. Monthly meetings are held.
- 35. In the field of social epileptic projects, Guatemala is one of the five pilot countries that the Pan American Health Organization selected to develop a program of primary care in epilepsy and has had national and regional meetings implementing the programs in the Region.
- 36. In Guatemala, the International Guidelines for the Manuals special written material distributed in the country including knowledge in epilepsy.
- 37. The international program of Mental Health Gap with attention to epilepsy has been developed and implemented in most of the subchapters of ILAE of Guatemala.
- 38. Together with the Mental Health Department of the Ministry of Health from Guatemala, programs for awareness on epilepsy are being done monthly.

- 39. The Pan American Health Organization's representative in Mental Health Diseases, Dr Rodriguez, has travelled several times to Guatemala to help develop the initiatives of reducing the GAP in the fight against epilepsy.
- 40. The local Chapter of the League has helped develop two epilepsy surgery programs. One with special funds from the Congress of Guatemala, representing a joint effort between the League Guatemala and other organizations. The organization that handles this project is named HUMANA and is headed by Dr Juan Carlos Lara, Dr Jose Manuel Perez and Dr Jorge Leon. The other epilepsy surgery program is based in the main state Hospital of Guatemala: Hospital General San Juan De Dios.
- 41. The International Congress on Chronic Neurological Diseases and Epilepsy took placed in Guatemala City in the 3rd week of August 2012 and had participants from Central America, South America and Europe.
- 42. Neuropsychology continues to develop in the area of epilepsy with two private universities presenting neuropsychological works and five different publications in the form of thesis published in the fields of epilepsy and neuropychology.
- 43. In the electronic media, three different web pages were created that have special publications on epilepsy and belong to our organizations in Guatemala: One is Neurologia para todos, the second is Neurociencias en Guatemala and Neurociencias in Guatemala.
- 44. Our Chapter has published four electronic publications and books in epilepsy and provides for public consultation on the Internet.
- 45. Our Chapter participated with posters and works in the recently finished Latin American Congress of Epilepsy held in Quito, Ecuador in 2012.

HUNGARIAN EPILEPSY LEAGUE (HEL)

Publications

Official Guideline of Epilepsy Care, by V Juhos, K Hollody and J Janszky (eds.). 2010

Meeting

2011

- HEL Section in frame of the XLV. Congress of Hungarian Clinical Neurophysiologic Society, 16-18 June, Miskolc
- 28th Hungarian Epilepsy Workshop, 10-12 November, Győr

2012

- 11th Biannual National Congress of HEL, 30 May-2 June, Kaposvár.
- 29th Hungarian Epilepsy Workshop, 18-20 October, Győr.

Summary of Activities in 2011 and 2012

- Election of Board: Jozef Janszky, President; Zoltan Szupera, Secretary General; Andras Fogarasi, President-elect; Judit Jerney, Past President
- Reevaluation and care of personal HEL qualifications 'Physician Trained in Epilepsy' (PTE) and 'Epilepsy Specialist' (ESP).
- In agreement with the Hungarian Association of Clinical Neurophysiology creation of a new HEL qualification "EEG license for PTE or ESP"
- Edition of supporting material for evaluation of redt working ability for PWE
- As a member of Owners Board participation in editing and publishing of Clinical Neuroscience / Ideggyógyászati Szemle (Ideggyogy Sz – IF/2011 0.488)
- The HEL submitted the proposal on the revision to the sporting license in people with epilepsy, to the Hungarian Society of Sports Medicine.

Summary of Activities in Relation to Global Campaign in 2011 and 2012

- Patronizing and supporting the European Epilepsy Day both years on 14 February
- Publications for patients and their families about epilepsy
- Stand Up for Epilepsy two photos were exhibited in European Epilepsy Congress in London, of leading sport personalities with children living with epilepsy (HEL representative: Judit Jerney, Past President)
- European Epilepsy Declaration 75 percent of the Hungarian MEPs signed the Declaration (HEL representative: Judit Jerney, Past President).

Educational Activities

- Teaching courses about modern diagnostic and therapeutic methods in epilepsy
- The HEL announced application for Donath prize.
 The aim of the award is to inspire the scientific and
 educational activities of the young physicians,
 students, and medical specialists in the field of
 epilepsy.

Activities in Conjunction with Local IBE Affiliate

- The Hungarian Association for the Future of People with Epilepsy has been a member of the IBE since 2007. HEL supported the activity of the organization in providing an umbrella function and coordinating the local Societies
- Patronizing the European Epilepsy Day.

Future Plans

- To continue the regular educational courses
- To elaborate the new standards of the quality control, for epilepsy care in Hungary
- To renew the homepage for the HEL.

Officer Election Date

2015

Report By

Jozef Janszky, (President) and Zoltan Szupera, (Secretary-General)

INDIAN EPILEPSY SOCIETY

Publications

Epilepsy India Newsletter Quarterly

Meeting

13th Joint Annual Conference of Indian Epilepsy Association Indian Epilepsy Society

Summary of Activities in 2011 and 2012

- Annual Conference in March 2012
- National Epilepsy Day Celebrated by various state Chapters, organized epilepsy camps in various states for epileptic patients and their caregivers
- EEG Workshop August 2012
- Epilepsy School December 2012 at Kochi, Kerala
- Epilepsy School planned November 2013 at New Delhi
- New Life members enrolled in 2012-2013 totaling 40.

Summary of Activities in Relation to Global Campaign in 2011 and 2012

National Epilepsy Day Celebrated by various state Chapters. Organized epilepsy camps in various states for epileptic patients and their caregivers

Educational Activities

• We organized 7th IES EEG Workshop, 11-12 August 2012 at New Delhi, India

- Indian Academy of Neurology and Indian Epilepsy Society organized Epilepsy School in November 2012 at Kochi, Kerala India
- We conducted the CMEs for young neurologist and epileptologist
- We had sent a team of eight neurologists to attend Epilepsy Olympiad which was held during the 10th European Congress on Epileptology 2012 from 30 September to 4 October 2012 at London, UK.

Activities in Conjunction with Local IBE Affiliate

National Epilepsy Day celebrated by various state Chapters. Organized epilepsy camps in various states for epileptic patients and their caregivers. Camps comprised of public lectures, play, sports and painting, etc.

Future Plans

Indian Epilepsy Society is planning to organize Epilepsy School from 20-23 November 2013 in New Delhi

Officer Election Date

April 2010

Report By

Dr Man Mohan Mehndiratta, Secretary-General

INDONESIA SOCIETY AGAINST EPILEPSY

Meetings

- Denpasar, 4 November 2011
- Jakarta, 3-4 December 2011
- Jakarta, 28 January 2012
- Jakarta, 3 March 2012
- Makassar, 9 November 2012.

Summary of Activities in 2011 and 2012:

- Five meetings
- Twelve educational activities
- Eight activities in conjunction with local IBE affiliate
- Make draft curriculum of epilepsy consultant
- Make a hospital-based research in epilepsy.

Summary of Activities in Relation to Global Campaign in 2011 and 2012:

- In conjunction with Ministry of Health, start a program for reduction of epilepsy treatment gap. Implemented in primary healthcare. October 2011
- Start a hospital-based research project in epilepsy, now in progress.

Educational Activities:

- 1. Revise The Guideline of Epilepsy: 2011.
- 2. Epilepsy Symposium in Conjunction with ASEPA Teaching Course, 11 June 2011 in Solo.
- 3. EEG Workshop in Conjunction with ASEPA Teaching Course, 10 June 2011 in Solo.
- 4. ASEPA Teaching Course, 12 June 2011 in Solo.
- 5. Epilepsy symposium: Jakarta March 2012.
- 6. Epilepsy: Symposium and workshop Malang, 28 April 2012.
- 7. Epilepsy symposium for fasting PWE: Jakarta, July 2012.
- 8. Epilepsy symposium: Yogyakarta August 2012.
- 9. EEG workshop: Jakarta, October 2012.
- 10. EEG workshop in Conjunction with ASEPA Teaching Course, 9 November 2012 in Makassar.
- 11. ASEPA Teaching Course, 10 November 2012 in Makassar.
- 12. Make draft curriculum of epilepsy consultant.

Activities in Conjunction with Local IBE Affiliate

- 1. 1st media seminar held on 15 December 2011, Jakarta: "Mari Hapus Stigma Negatif Epilepsi" (Let's vanish the negative stigma of Epilepsy).
- 2. 2nd media seminar held on 21 March 2012, Jakarta: "Patuh pada Pengobatan Agar Epilepsi Terkontrol" (good compliance for good control of epilepsy).
- 3. Purple Day: Gathering and epilepsy symposium for PWE and their family in Jakarta, Surabaya, Bandung, Semarang, Manad, March 2012.
- 4. Epilepsy case finding: by medical students and teachers in rural area: Jombang, East Java: June 2012.
- 5. 3rd media seminar (winner announcement) on 14 June 2012, Jakarta: "Tatalaksana yang tepat sangat diperlukan untuk mengontrol serangan pada PWE" (Epilepsy Management).
- 6. Epilepsy symposium for public, 3 November 2012 in Solo.
- 7. CSP Customer Support Program, Support PWE for a good compliance.
- 8. Epilepsy symposium for fasting PWE: Jakarta, July 2012.

Future Plans

- Revise Guideline of Epilepsy
- Education of people, teachers, and police about epilepsy to increase epilepsy awareness
- Education of Health Professionals about epilepsy, to increase management of epilepsy
- Reducing treatment gap, in conjunction with Ministry of Health.

Officer Election Date

2015

Report By

Dr Kurnia Kusumastuti, dr., Sp.S(K), President

IRAQI SOCIETY AGAINST EPILEPSY

Summary of Activities in 2011 and 2012

- One-day symposium held in conjunction with Al-Mustansyria Medical College and Al-Yarmook Teaching Hospital under the title of 'Pitfalls in the Management of Epilepsy' in 2012.
- Monthly meetings on the last Wednesday of each month with one or two lectures presented by Chapter members about epilepsy issues together with monthly administrative meetings.
- 3. Ongoing work by Chapter members to establish the 'Iraqi Guidelines in the Management of Epilepsy.'
- 4. Active participation of Chapter members in the 2nd Iraqi Neuroscience Symposium in Al-Kufa University Medical College in 2011.
- 5. Active participation in the 'Baghdad Medical College Annual Conference' in 2012.
- 6. Active participation in the 3rd Iraqi Neuroscience Symposium 2013 at the Al-Kufa University College.

Summary of Activities in Relation to Global Campaign in 2011 and 2012

- 1. Active participation in the 'Fifth Epilepsy Symposium' held in Paris in 2012.
- 2. Participation in the 'Stand up for Epilepsy Exhibition' at the London Congress in 2012.
- 3. Active participation in the '7th Epilepsy Symposium' held in Beirut in 2013.

Educational Activities

- 1. A number of lectures presented at different hospitals in Iraq by Chapter members about 'Seizure First Aid' and epilepsy management.
- 2. A number of TV meetings in the Iraqi space canal for public education.

Future plans

- 1. One-day symposium about 'WWE (Women With Epilepsy)' to be held on March 2013 in conjunction with 'Iraqi Society of Gynae.'
- 2. Active participation in the '1st Conference for Iraqi Neurology Society in February 2013.
- 3. The 2nd Conference for 'The Iraqi Chapter Against Epilepsy' in April 2013.

Officer Election Date

March 2015

Report By

Dr Ghaieb Bashar Aljandeel, Vice President

IRISH EPILEPSY LEAGUE (IEL)

Meeting

4 November 2011 and 2 November 2012

Summary of Activities in 2011 and 2012

In 2011 the IEL began a membership drive to encourage all professionals working for patients with epilepsy in Ireland to join and get involved in the work of the IEL, locally, nationally and internationally. At the beginning of 2012 membership had risen by over 50 percent and continues to rise. The IEL made a decision to become more actively involved in professional activities which would assist people involved in the care of people with epilepsy to network and also enable the IEL to advocate for additional epilepsy resources. To help achieve this aim the IEL organized two very successful Epilepsy Expert Days which show-cased the work and developments in epilepsy by professionals at national and international levels.

Summary of Activities in Relation to Global Campaign in 2011 and 2012

The IEL actively supported Brainwave, The Irish Epilepsy Association, activities for European Epilepsy Days and other advocacy campaigns in 2011 and 2012.

Educational Activities

2011 - First Epilepsy Expert Day: The IEL organized this day in order to become more actively involved in professional activities, to aid in the networking of people involved in the care of people with epilepsy and related disorders, to provide a voice in international activities of the ILAE, to promote advocacy for epilepsy resources and to obtain research funding for epilepsy at national and European levels. There was a diverse range of Irish and UK speakers at this inaugural event including: "Epidemiology of the Epilepsies," by Dr Christine Linehan, Director of the National Institute for Intellectual Disability, Trinity College Dublin; "The Heart Brain Connection in Epilepsy," by Dr Elijah Chaila, Consultant Neurologist, Midlands General Hospital; "New and Emerging MRI Techniques in the Evaluation of Epilepsy," by Dr Fergus Rugg-Gunn, Consultant Neurologist, National Hospital for Neurology and Neurosurgery, London; "Use and abuse of EEG" by Dr Gerard Mullins, Consultant Neurophysiologist, Beaumont Hospital; "New Insights into the Aetiology of the Epilepsies," by Dr Danny

Costello, Consultant Neurologist, Cork University Hospital; "What's new in Pediatric Epilepsy?," by Dr Sophie Varadkar, Consultant Pediatric Neurologist Great Ormond St Hospital for Children NHS Trust, London; "The Art of Tweaking in AED Combination Therapy," by Prof Martin Brodie, Director, Epilepsy Unit, Western Infirmary, Glasgow, Scotland; "The future of epilepsy care in Ireland," by Dr Colin Doherty, Consultant Neurologist, St James Hospital; and the day was closed by Mr Mike Glynn, CEO Brainwave and IBE President. The IEL organized this day in conjunction with UCB Pharma.

2012 - Second Epilepsy Expert Day: A goal of IEL President Prof Norman Delanty was to make the Epilepsy Expert Day an annual event. This ambition was realized when a second day was held in November 2012. This meeting was organized in conjunction with Eisai Europe Ltd. This annual Expert Day for epilepsy is now a focal point for increasing ILAÉ activity within Ireland. The day was chaired by the IEL President and speakers included: "Approach to the patient with new onset seizures," by Dr Kevin Murphy, Consultant Neurologist, Sligo General Hospital; "Personalized Medicine: Using clinical factors to predict outcomes and inform driving," by Prof Tony Marson, Professor of Neurology, Reader in Neurology University of Liverpool, Honorary Consultant Walton Centre; "VNS and other devices in epilepsy management," by Prof Paul Boone, Professor of Neurology, Ghent University Hospital, Belgium; "Update on the National Epilepsy Care Program," by Dr Colin Doherty, Consultant Neurologist, St James Hospital; "Epilepsy Genetics Research in Ireland," by Dr Gianpiero Cavalleri, Biomedical Research, Royal College of Surgeons Ireland, Dublin; "Non-Epileptic attack disorder: An Epileptologists perspective," by Dr John Paul Leach, Consultant Neurologist, Southern General Hospital, Glasgow; "Epilepsy in pregnancy What's new?," by Dr John Craig, Consultant Neurologist, Royal Victoria Hospital, Belfast; and concluded with Mr Mike Glynn, CEO Brainwave and IBE President who presented on the work of Brainwave and IBE developments in Europe.

Activities in Conjunction with Local IBE Affiliate

The IEL was delighted to showcase the IBE Jubilee Photographic Exhibition 'Epilepsy Without Words' at the 1st Epilepsy Expert Day, and would like to thank Brainwave, The Irish Epilepsy Association and IBE affiliate for their assistance in obtaining the exhibition. The IEL and Brainwave, local IBE affiliate, are both actively involved in the HSE National Epilepsy Clinical Care Program launched in May 2010, which has as a central tenet the creation of a new cohort of Epilepsy Nurse Specialists, trained to Advanced Nurse Practitioner level in a newly designed epilepsy masters

course in the Royal College of Surgeons in Ireland. The main goal of this program is to change epilepsy care in Ireland with a model of care delivery, which will be underpinned by access to specialist nurses, improvements in quality, access and cost.

Future Plans

2013 – European Forum on Epilepsy Research IEL members will actively participate at the first European Forum on Epilepsy Research which will take place in the Convention Centre, Dublin from 25-27 May 2013 as part of the Irish Presidency of the European Union. The forum will have three definite goals 1) more focused research funding, to improve diagnosis and treatment; 2) Raise public awareness and reduce stigma associated with epilepsy and 3) Access to optimal standards of care across Europe, for people with epilepsy. This forum will bring together leading epilepsy researchers and policy makers to discuss a coordinated strategy for epilepsy research in Europe. For further details please visit the Conference website www.epilepsyresearcheurope.org

Report By

Professor Norman Delanty, President

JAMAICAN LEAGUE AGAINST EPILEPSY (JLAE)

Summary of Activities in 2011 and 2012

During 2011 three main objectives were achieved.

- The first was the creation of the teleconferencing facility at the University Hospital of the West Indies, funded locally in Jamaica and spearheaded by Prof. Ivor Crandon, Head of the Department of Surgery. The facility was launched with a link to Yale in July 2011
- Much of the year was also spent working on funding and the logistics of holding the Third North American Regional Caribbean Congress on Epilepsy elsewhere than Jamaica where the first two Congresses were held
- Pr Ali, President of the JLAE also worked closely with Profs Sam Wiebe, Nico Moshé and Peter Wolf in the development of a unique Constitution and Bylaws that would permit the unification of the islands and territories of the Caribbean in a common Society, the Epilepsy Society of the Caribbean (ESC). This would not have been possible without the prior approval by the ILAE that would permit the formation of such a multi-nation Chapter. The JLAE has, since its inception in 2001, had affiliate members from many of the other Caribbean islands. However the desire to have a fully inclusive society that would permit the regional

harmonization of efforts to improve epilepsy care led to the conceptualization of the ESC. The Constitution and Bylaws were approved and announced in Antigua by Prof Emilio Perucca, then President-elect of the ILAE at the Third North American Regional Caribbean Congress on Epilepsy (Third NARCCE) held in February, 2012. This Congress, now with Category 1 CMEs, was well-attended and enthusiastically received. Faculty from North America and the Caribbean delivered high quality regionally relevant presentations. This Congress has cemented a place in the calendar of the Caribbean Region and is now a much anticipated biennial event. The fourth NARCCE will be held in St Lucia in 2014.

In 2012

- The teleconference facility has been actively functioning, with alternate weekly teleconferences with the Yale epilepsy group. While epilepsy surgery itself has not yet begun in Jamaica the regular teleconference meetings has catalyzed the creation of an Annual Course on Epilepsy at the University of the West Indies in Jamaica, a series of 16 lectures covering the subject from a multidisciplinary perspective. This Conference has been freely open to all interested students, residents and attendings and is generating significant interest in the field among students. Also, in July 2012, Drs Tammy Haynes-Robinson, neuropsychologist and Dr Geoffrey Liburd, neurosurgeon, travelled to Yale University for a year of specialized training that, on their return to Jamaica, the epilepsy surgery program can begin in earnest. The JLAE remains extremely grateful to the North American Commission for its support of this initiative as well as to Yale and Dr Dennis Spencer in particular for all his personal efforts to support the development of this surgical program in Jamaica
- As this report is being written, the votes for the elected Executive members of the Council of the ESC have just been tallied. The Executive will be in office for two years. The president will not be eligible for re-election but will serve an additional term as Immediate Past-President. We are looking forward to immediately forming active subcommittees to continue the work started by the JLAE on important areas of future emphasis such as regional research, educational initiatives and the development of the surgical program
- An important subcommittee we will form is one to promote the rights of people with epilepsy to be legally able to hold a driver's license once seizurefree, a right they currently are denied all across the English-speaking Caribbean

- We are also greatly looking forward to the Epilepsy Society of the Caribbean becoming an active member of the North American Region of the ILAE, as the JLAE has been
- Finally, this is the final report that will be written on behalf of the JLAE which has as of today been absorbed into this larger regional Society. The JLAE was formed only 11 years ago but we believe did achieve the important objective of raising awareness of the needs of people with epilepsy in the Caribbean and, by working closely with our North American colleagues, particularly through the North American Commission, helped to raise standards of diagnosis and treatment across Jamaica and the Caribbean Region during its relatively short existence.

Activities in Conjunction with Local IBE Affiliate

Annual Fun Run to raise funds for epilepsy care; held in Kingston, Jamaica in December 2012.

Future Plans

The JLAE as of today has been absorbed into the regional Epilepsy Society of the Caribbean.

Report By

Amza Ali, President JLAE

JAPAN EPILEPSY SOCIETY (JES)

Summary of Activities in 2011 and 2012

- The first joint symposium organized by JES and Japanese Association for Acute Medicine (JAAM) was held at the 40th Annual Meeting of Japanese Association for Acute Medicine (JAAM). The necessity of multidisciplinary epilepsy care, especially for adult epilepsy, is gaining recognition. The issues of treatment for patients with childhood onset epilepsy who reach adulthood (awareness of the status of carry-over care) are being highlighted.
- 2. The number of JES members continues to increase. As of 10 January 2013, membership has further increased to 2,448, with more pediatricians, neurosurgeons and neurologists joining JES.
- 3. Including the 42 epileptologists who passed the certification examination in 2012, a total of 437 clinical epileptologists certified by the JES are now practicing. With the need to address the increase in elderly onset epilepsy, the current number of specialists is totally inadequate. Further measures to increase the number of certified epileptologists have to be considered.

- 4. The 46th Annual Conference of the JES was held 10-11 October 2012 in Tokyo under the leadership of the chair Prof Masato Matsuura. Over 1,200 participants attended the meeting, who actively discussed and shared views. The number of attendees exceeded 1,200 for the second time in the history of the JES Annual Conference. The Conference was witness to the continued increase in interest on epilepsy care in recent years.
- 5. The JES Sponsored Award continues to be active, with nine young JES members awarded study tours to North America and other Regions. The JES Scholarship also continues to accept young researchers in the Asian Oceanian region to study in Japan.
- To prevent traffic accidents related to epileptic seizures, the Legislative Affairs Committee of JES is engaged in survey and preventive activities in collaboration with the National Police Agency and other related bodies.
- 7. The JES in collaboration with the Japan Medical Association is constructing an epilepsy care network that transcends the boundaries of medical disciplines and regions. During the 12 months starting from April 2012, approximately 40 courses on epilepsy are to be held all over Japan.

Report By

Masako Watanabe

JORDANIAN CHAPTER OF EPILEPSY

Meetings

Four meetings

Summary of Activities in 2011 and 2012

We have done four meetings in 2012. They were successful and interactive. Most of the audience were doctors of different specialties and students of the medical school of Hashimet University. We also arranged three lectures on the subjects of treatment update, difficult cases in epilepsy and when to start antiepileptic treatment. These three lectures were done by Dr Mohammed Shehab.

Educational Activities

Lectures for medical students of Hashimate University

Future Plans

We are planning to arrange a symposium on 28 February to 1 March 2013 in the Kempinski Hotel in the Dead Sea and we have the pleasure to invite you to this activity which will be regional.

Officer Election Date

By the end of 2013

Report By

Dr Mohammed Shehab

KOREAN EPILEPSY SOCIETY

Publications

Journal of Epilepsy

Summary of Activities in 2011 and 2012

- 1. Korean Epilepsy Congress 2012, 7-9 June 2012 in SongDo Convensia, Incheon, Korea.
- 2. Proclamation of Epilepsy 2012, 7 June 2012 in Deoksu-gung, Seoul, Korea.
- 3. Press conference for Epilepsy 2012, 7 June 2012 in Plaza Hotel, Seoul, Korea.
- 4. Epilepsy PR forums 22 March 2012 in Severance Hospital, Seoul, Korea.
- 5. Epilepsy promotional activities 10-15 December 2012 Five Korean Newspapers.
- 6. Policy Conference for people with epilepsy.

Summary of Activities in Relation to Global Campaign in 2011 and 2012

- 1. Meeting AOEC in Manila.
- 2. International sports star and epilepsy patients with Taking Pictures.

Educational Activities

- 1. Supplement Education 2012, 24 November 2012 in Seoul Asian Hospital, Korea.
- 2. Education for Epilepsy to teachers and civil servants.
- 3. Opened EEG test.

Activities in Conjunction with Local IBE Affiliate

1. Proclamation of Epilepsy 2012, 7 June 2012 in Deoksu-gung Seoul, Korea.

Future Plans

- 1. Korean Epilepsy Congress 2013, 13-15 June 2013 in Grand Hotel, Seoul, Korea.
- 2. Korean Bureau for Epilepsy (KBE), expected to start.
- 3. Supplement Education 2012, 2 November 2013 in Severance Hospital, Seoul, Korea.

Officer Election Date

19 March 2013

Report By

Hoon-Chul Kana

ASSOCIATION AGAINST EPILEPSY OF KOSOVO

Meeting

Several professional meetings related to epilepsy with the local members

Summary of Activities in 2011 and 2012

The Association Against Epilepsy of Kosovo was created in 2010. In 2011 it became a full member of the International League Against Epilepsy (ILAE). Membership in ILAE was a special moment for the Association and a big encouragement to intensify its activities. After membership in ILAE, the Association's leadership held a series of meetings where an action plan for the year 2011 and 2012 was created. Firstly, the Association's board created a working group to design a logo for the Association, as well as to draft the frame of the Association's website. Both of these activities were carried out successfully and today the League Against Epilepsy of Kosovo has its logo, and website, which is expected to be launched in February. During the year 2011 and 2012, the Association Against Epilepsy of Kosovo has organized a total of six professional meetings with its members, three meetings each year. These meetings had educational purposes for the members of the Association. For the purpose of awareness raising, education and increasing knowledge about epilepsy, during the year 2011 and 2012, the League Against Epilepsy of Kosovo held two meetings with patients with epilepsy and members of their families (one meeting per year). During 2011 and 2012, four radio programs were broadcast from the national radio station, where topics related to epilepsy issues were discussed. These radio programs were broadcast with the purpose to raise awareness among the general population about epilepsy and the challenges it brings. The lack of a meaningful data base of patients with epilepsy in the Republic of Kosovo has pushed us, as an Association, to establish a partnership with the Ministry of Health. Several meetings were held with officials of the Ministry of Health where we discussed several modalities related to the creation of a data base of people with epilepsy in Kosovo.

Educational Activities

The Association Against Epilepsy of Kosovo has organized several educational activities. Target groups for these activities have been professionals who deal with epilepsy and its treatment, patients with epilepsy, their families, officials of various institutions, policy makers in the field of health as well as the general population. Below we present educational activities organized by year:

2011

- Organization of three professional meetings with members of the Association Against Epilepsy of Kosovo. Topics of discussion at these meetings were:
 - Epilepsy and pregnancy
 - Complications of antiepileptic therapy
 - Stroke and epileptic seizures.

The purpose of these meetings was to increase the knowledge of medical professionals who deal with the diagnosis and treatment of epilepsy, share new principles of epilepsy treatment during pregnancy, possible complications and side effects of antiepileptic medications as well as information on the occurrence of epilepsy after stroke and its treatment.

- 2. Organization of a meeting with patients with epilepsy and their family members The purpose of this meeting was information and awareness raising and delivery of basic knowledge to patients with epilepsy and their families about what epilepsy is, how it is diagnosed, possible treatments, first aid in the event of an epileptic seizure, as well as general information on living with epilepsy.
- 3. Two radio programs were broadcast on the national radio station (one per year). These 45-minute programs were broadcast live with the intention to grab the attention of the listeners and give them the opportunity to ask question and interact on the topic of epilepsy. The main purpose of these programs was to raise the knowledge and awareness of the general population on epilepsy, challenges that it can bring, the stigmatization of people with epilepsy, their rights, and the difference of epilepsy from mental illness.

2012

- Organization of three professional meetings with the members of the Association Against Epilepsy of Kosovo. Topics of discussions at these meetings were:
 - Novel epilepsy therapies
 - Rational polytherapy with antiepileptic drugs
 - Multiple sclerosis and epilepsy.

The purpose of these meetings was to increase the knowledge of medical professionals who deal with the diagnosis and treatment of epilepsy, to get familiar with new antiepileptic medicines and the advantages and disadvantages of novel antiepileptic medications compared to antiepileptic medications of older generation, as well as the latest news on handling epilepsy. In the second meeting, the importance of rational polytherapy and finding and combining of antiepileptic medications which have favorable characteristics and challenges in finding optimal combinations

was discussed. In the third meeting, epilepsy seizures in multiple sclerosis patients was discussed. In this meeting, a scientific study carried out by a group of neurologists of Neurology Clinic at the Clinical University Centre of Kosovo in Pristine, was presented.

- 2. Organization of a meeting with patients with epilepsy and their family members.
 - The purpose of this meeting was information, raising awareness and delivery of basic knowledge to patients with epilepsy and their families about what epilepsy is, how it is diagnosed, possible treatments, first aid to be given in the event of an epileptic seizure, as well as life with epilepsy.
- 3. Two radio programs were broadcast on national radio (one per year). These 45-minute programs were broadcast live with the possibility of receiving questions from listeners. The purpose of these programs was to raise the knowledge and awareness of the general population on epilepsy, challenges that it can bring, the stigmatization of people with epilepsy, their rights, and the difference of epilepsy from mental illness.

Future Plans

- Launching of Association's website
- Organization of activities for European epilepsy Day (11 February 2013)
- Marking of Purpled Day
- Three professional meetings
- Creation of a database of people with epilepsy
- Organize an educational campaign for high school students
- Continue public awareness-raising by utilizing mass media
- Enhance our educational activities by starting to prepare for running an epilepsy course and/or organizing a symposium.

Officer Election Date 2011

Report By

Valbona Govori, President

KUWAIT LEAGUE AGAINST EPILEPSY

Meeting

8th GCC Neurology Conference, 16-17 November 2012

Summary of Activities in 2011 and 2012

• The Chapter was formed in March 2013

- Purple Day 2011
- Purple Day 2012
- Seminars on "Epilepsy, Beyond medical therapy"
- 9 June 2012, Multiple TV and Radio interviews on epilepsy for public awareness.

Educational Activities

- Multiple single talks to medical practitioners and trainees on epilepsy
- Seminars on "Epilepsy, Beyond medical therapy"
- 9 June 2012, Educational poster prints on AEDs.

Future Plans

EEG workshop, epilepsy management seminars, Purple Day 2013

Officer Election Date

5 March 2011

Report By

Abdulaziz Ashkanani

MALAYSIAN SOCIETY OF NEUROSCIENCES (EPILEPSY COUNCIL OF MALAYSIA)

Meetings

A total of three meetings were held: 8 March 2011; 28 May 2011; and 1 November 2012

Annual AGM held in May 2011 during Malaysian Society of Neurology (MSN) AGM and all three existing office bearers will continue for another term (2012-2013)

Next annual AGM will be held in June 2013 during MSN AGM

Objectives

- 1. To promote education and training of health professionals in the care of epilepsy patients.
- 2. To promote research in epilepsy.
- 3. To continue to improve care in epilepsy management.

Summary of Activities

1. Epilepsy Awareness Campaign

The school epilepsy program hit a snag when the personnel in the Ministry of Education changed portfolio. No campaign was carried out in 2011 although the Epilepsy Council of Malaysia (ECM) has received partial funding from the Neuroscience Foundation in December 2009 and December

2010. The council decided to put the campaign on hold until after the national general election. Dr Datuk Raihanah was interviewed on epilepsy by Metro Harian, which was organized by Pantai Hospital.

2. Educational Activities

A series of workshop and lectures were conducted by ECM members to other healthcare professionals throughout 2012.

By Prof Dr Dato' Raymond Azman Ali:

- Delivered a lecture entitled "Management of epilepsy in Malaysia" at the GSK round table discussion with Prof Patrick Kwan on Epilepsy Disease Burden and Treatment Option, Hilton Hotel, Kuala Lumpur, 25 February 2012.
- ii. Delivered four lectures to Year 2 medical students at Universiti Sultan Zainal Abidin, Kuala Terengganu, 17 May 2012 entitled "Cranial nerve disorders," "Differential diagnosis of blackouts," "Clinical approach to epilepsy" and "Diagnostic approach to weakness."
- iii. Delivered a lecture entitled "Psychogenic Non-Epileptic Seizures" at the 8th Kuala Lumpur Mental Health Conference, organized by the Badan Kebajikan Psikiatri, Putra World Trade Centre, Kuala Lumpur, 4 July 2012.
- iv. Delivered a lecture entitled "Differential Diagnosis of Blackouts" at Neuroscience 2012, the 23rd Annual Scientific Meeting of the Malaysian Society of Neurosciences, Pullman Hotel, 8 July 2012.
- v. Delivered a lecture entitled "Approach to Fits, Faints and Funny Turns" at the Penang Neurology Update, Penang Hospital, 13 July 2012.
- vi. Delivered a plenary lecture (as Tokoh Penyelidik) entitled "The Molecular Basis of Epilepsy" at the 14th Research Week of the Health Sciences, UKM, 16 July 2012.
- vii. Delivered a lecture entitled "Semiology of spells and seizures" at the Johor Neurology Update, Monash University Clinical Campus, Johor Bahru, 13 October 2012.
- viii. Delivered a lecture entitled "Semiology of Generalized Seizures" at the Asian Epilepsy Academy (ASEPA) Teaching Course in "Classification, Semiology and Differential Diagnoses of Seizures and Epilepsies," Makassar, Indonesia, 11 November 2012.
- ix. Delivered a lecture entitled "Other Differential Diagnoses of Seizures and Epilepsies" at the Asian Epilepsy Academy (ASEPA) Teaching Course in "Classification, Semiology and Differential Diagnoses of Seizures and Epilepsies," Makassar, Indonesia, 11 November 2012.

By Assoc Prof Dr Tan Hui Jan:

- i. Neuro Update: Epilepsy and Status Epilepticus. Academy of Medicine, 21 April 2012.
- ii. East Coast Neurology Update. 24 May 2012, Hotel Permai, Kuala Terengganu.
- iii. EEG monitoring in localization. 6-8 July 2012 MSN Pullman Putrajaya.
- iv. Seizures and CNS infection. 6-8 July 2012, MSN Pullman Putrajaya.

By Dr Datuk Raihanah Abdul Khalid:

- Delivered a lecture entitled "Seizures When the drugs don't work" at GP & Physician workshop, Grand Dorsett Hotel, Subang Jaya, in October 2012
- ii. A talk on epilepsy as part of lecture series for Post-Graduate Nurses' program in critical care and another one on Status Epilepticus, at the Tun Tan Cheng Lock College of Nursing, PJ throughout September October 2012.
- Epilepsy awareness talk to Parents-Teachers Association at Sekolah Sungai Dua, Penang, June 2012.

By Assoc Prof Dr Wong Sau Wei:

Delivered a lecture entitled "Benign Epilepsies in Childhood" at East Coast Neurology Update, 24 May 2012, Hotel Permai, Kuala Trengganu

By Dr Ahmad Rithauddin:

- Delivered a lecture entitled "Update on Treatment of Intractable Epilepsies" An Update of Pediatric Neurology 2012, 23-25 September, 2012, Auditorium, Kota Bahru Nursing College, Kota Bahru
- ii. Delivered a lecture entitled "Common Pediatric Epilepsy Syndromes" Pharmacy Practice Scientific Conference, 23 March 2012, Hotel Istana, Kuala Lumpur.
- iii. Delivered a lecture entitled "Fits, Faints and Funny Turn." Pediatric Workshop for GPs organized by UBM Medica, 1 July 2012, Hotel Saujana, Subang Jaya.
- iv. Delivered a lecture entitled "EEG Monitoring in Children," at the 23rd MSN Annual Congress, 6 July 2012, Hotel Pullman, Putrajaya.
- 3. Consensus Guidelines on Epilepsy
 The council launched the updated Epilepsy
 Consensus Guidelines 2010 during the MSN
 Annual Scientific meeting 2010 in Kota Kinabalu.
 The electronic copy of the guideline is available on the MSN website.

4. Research in Epilepsy

Although no new research was conducted, the ECM received a research grant of RM20,000.00 from Novartis Corp (M) San Bhd to conduct research for HLA-B*1502 testing. The ECM called for research proposals for cross-validation studies from five institutions throughout Malaysia that were capable of performing the test in-house. The ECM received proposals from two institutions (UKMMC and UITM) and a letter from the Institute of Medical Research (IMR) containing a counter suggestion to this research initiative. As there was no further response from UITM requesting ethics approval of research proposals, the council decided to allocate all the research funding to UKMMC. The test kit is still in progress and is expected to be ready for commercialization by 2013.

Report By

Loh Hui Pin and Prof Dato' Dr. Raymond Azman Ali

EPILEPSY SOCIETY OF MALTA

Summary of Activities in 2011 and 2012

In 2011 and 2012 the Epilepsy Society of Malta worked closely with the IBE member association, the Caritas Malta Epilepsy Association, to raise more public awareness about epilepsy in Malta including talks, media appearances and conferences. The new Neuroscience Department at the main teaching hospital also began more teaching activities for young medical graduates and graduate trainees which included discussion of epilepsy cases.

Educational Activities

The Epilepsy Society of Malta and the Caritas Malta Epilepsy Association participated in in-service training for educators and teachers in Malta in conjunction with the Ministry of Education. A national conference was also held on raising awareness among employers about epilepsy.

Activities in Conjunction with Local IBE Affiliate

European Epilepsy Day activities were held on the University of Malta campus in conjunction with the Malta medical students, Malta pharmaceutical students and Malta Dental students associations.

Future Plans

More training sessions on epilepsy surgery for young medical trainees are planned.

Officer Election Date

2012

Report By

Janet Mifsud, Secretary

MEXICAN LEAGUE AGAINST EPILEPSY (CAMELICE)

Publications

Books:

- 1. Epilepsia. Rubio-Donnadieu F, Alonso-Vanegas M, Reséndiz-Aparicio JC, Sentíes-Madrid H 2011.
- 2. Epilepsia un enfoque actual. Sentíes-Madrid H. Ed. Alfil. 2012.

Meetings

- 1. XXXIV Annual Meeting Oaxaca 2011.
- 2. Neurociencies in epilepsy meeting. April 2012.
- 3. XXXV Annual Meeting, Durango. September 2012. (965 participants).

Summary of Activities in 2011 and 2012

- 1. PAHO activities.
- 2. Participation in the International Affairs Committee of the American Epilepsy Society.
- 3. Participation in the Task Force in ILAE Epilepsy Guidelines.
- 4. CAMELICE website.
- 5. Participation in AES PECA program (posters presentation in AES Annual Meeting 2011 and 2012), European Epilepsy Meeting 2012 and Latinoamerican Epilepsy meeting.

Summary of Activities in Relation to Global Campaign in 2011 and 2012

- Promotion of Global Campaign in the CAMELICE website.
- 2. PAHO activities.

Educational activities

- 1. XXXIV Annual Meeting Oaxaca 2011.
- 2. Neurociencies in epilepsy meeting. April 2012.
- 3. XXXV Annual Meeting, Durango. September 2012. (965 participants, 13 international professors).

Future Plans

- 1. Epilepsy information Book for patients and caregivers.
- XXXVI Annual Meeting in Veracruz, September 2013.

Officer Election Date

17 September 2012

Report By

Horacio Senties Madrid MD, President

MONGOLIAN EPILEPSY SOCIETY (MES)

Publications

- 1. Purevsuren T, Tovuudorj A, "The study of some causes, risk factors and Clinical findings of children with epileptic syndrome" Korean Epilepsy Congress, 2012. pp172.
- Khandmaa D Tovuudorj A "Knowledge, attitudes towards epilepsy among healthcare professionals" Korean Epilepsy Congress, 2012. pp 208.

Meeting

- 1. "Epilepsy Colloquium in 2012" in Ulaanbaatar.
- 2. "The 1st International Epilepsy Symposium" in Ulaanbaatar in 2012.

Summary of Activities in 2011 and 2012

The First International Epilepsy Symposium was organized 21-22 of September, 2012, in Ulaanbaatar. The first day event was held in the Blue Sky Hotel and Tower and the second day event was held in Jargalant complex. In the symposium the renowned scientists and professors from the CAOA and ASEPA participated and delivered lectures about modern conceptions of diagnosis and treatment of Epilepsy.

Summary of Activities in Relation to Global Campaign in 2011 and 2012

We consider that organizing the 1st International Epilepsy Symposium was very significant to improve collaboration and to advance relations between the World Health Organization (WHO), the International League Against Epilepsy (ILAE), the International Bureau for Epilepsy (IBE) and Mongolian Epilepsy Society (MES). The symposium was a part of the activity of the Global Campaign against Epilepsy "Out of the Shadows" which is jointly organized by WHO, ILAE, and IBE.

Educational Activities

Prof H Stefan (from Erlangen Epilepsy Center, Germany) visited Mongolia in 2011 and delivered a lecture about modern conceptions of diagnosis and treatment of epilepsy.

Activities in Conjunction with Local IBE Affiliate

We have been actively cooperating with IBE and organized the series of "Quality of Life" trainings in rural areas and cities.

Future Plans

We propose to implement the National Program on the Improvement of Epilepsy Care and Overcoming the Treatment Gap in Mongolia. This program, upon adoption by Mongolian government, shall be implemented stage by stage, depending on the availability of funding. The important milestone for success of this program shall be to establish the third level epilepsy center in UB with all related facilities in accordance with international requirements.

Officer Election Date

2014

Report By

Tovuudori, Secretary-General

NEPAL EPILEPSY SOCIETY

Meeting

Three meetings from April to December

Summary of Activities in 2011 and 2012

- 1. Health camp: Bhaktapur, Katunje, examined over 100 patients, 15 December 2012.
- Participation and lecture by President Dr Rabindra Shrestha: Analysis of Patients with Fainting Attack and Psychogenic Nonepileptic Seizure in a Tertiary Hospital.
- 3. One-day Conference on Epilepsy: Hotel Annapurna (sun): 24 August 2012.
- 4. Election of new board: April 2012.

Educational Activities

Participation and lecture by President Dr Rabindra Shrestha: Analysis of Patients with Fainting Attack and Psychogenic Nonepileptic Seizure in a Tertiary Hospital One-day conference on Epilepsy: Hotel Annapurna: 24 August 2012

Activities in Conjunction with Local IBE Affiliate

Health camps in collaboration with Nepal Epilepsy Bureau by February 2013

Future Plans

Development of Epilepsy Guidelines for the country by the end of June

Health camps: two more by June

Health camps in collaboration with Nepal Epilepsy

Bureau

Officer Election Date

New election completed April 2012

Report By

Dr Rabindra Shrestha

DUTCH LEAGUE AGAINST EPILEPSY (NETHERLANDS)

Publications

Annual Report

Meeting

Three to four meetings each year

Summary of Activities in 2011 and 2012

The Dutch League became the Epilepsy Task Force of the Dutch Neurology Association. There is an intense cooperation with the Dutch epilepsy patient organization and the National Epilepsy Federation. The vagal nerve stimulation group was integrated within the League.

Summary of Activities in Relation to Global Campaign in 2011 and 2012

Introduction of a website www.epilepsieliga.nl

Educational Activities

Organization of a National Epilepsy Symposium each year

Activities in Conjunction with Local IBE Affiliate

An app for epilepsy was introduced.

Future Plans

More attention for driving regulations for people with epilepsy, in agreement with European regulations

Report By

G Hageman, Neurologist, Secretary

NICARAGUAN CHAPTER (CANILICE)

Publications

Ninguna

Summary of Activities in 2011 and 2012

Two seminars, each year, for primary care physicians, to provide the basic tools for diagnosing and treating patients with epilepsy, with emphasis on rural and suburban areas. American Congress of Neurology, which included modules in pediatric epilepsy, drug resistant epilepsy and epilepsy and special conditions.

Educational Activities

Seminar for primary care physicians entitled "Basic Epilepsy: diagnosis, management and treatment," which took place in February and August 2012

Activities in Conjunction with Local IBE Affiliate

No Chapter of IBE

Future Plans

We are working with a group of civil societies, with the intention of organizing a foundation to ensure medications get to patients with epilepsy and to introduce laws to protect the rights of patients with epilepsy. We are currently drafting statutes and regulations to introduce to the appropriate authorities.

Officer Election Date

Pending

Report By

Foad Hassan

NIGERIA LEAGUE AGAINST EPILEPSY

Meeting

Nigeria Epilepsy Congress

Summary of Activities in 2011 and 2012

Nigeria is a Federation of 36 states with a federal capital territory, Abuja. As of 2010, there were over 35,000 doctors, 27 colleges of medicine and 75 tertiary and secondary medical institutions licensed to train medical house officers. The total number of consultant neurologist/physicians is 100-150 and there

may be the same number of psychiatrists. The number of neurosurgeons may be 50-100. All neurologists (pediatric and adult neurologists are trained to care for epilepsy patients as part of the training curriculum). Trained epileptologists are few, however some are in training. Our Chapter began in 2007 with an application made by the current president Dr IO Onwuekwe requesting permission to start a Nigeria Chapter. The Chapter was granted full membership in ILAE in 2011. We are one of the founding Chapters of the African Commission.

We participated in IEC Rome 2011 and in the first African Epilepsy Congress in Nairobi in 2012.

From the onset we adopted a five-point agenda coded RAATE (Research, Advocacy, Awareness Creation, Training, Education), which has been pursued for the past two years. The Chapter has been involved in several programs focused on public education.

The major highlight of our activity was the May 2012 Congress at Owerri-Owerri 2012. This Conference was attended by close to 50 people including more than 30 doctors. Also in attendance were students, nurses, pharmacists and other health workers. The theme of the Conference was epilepsy in the community with the guest lecture given by Prof M C Nwosu of the Nnamdi Azikiwe University Teaching Hospital Nnewi, in Anambra State of Nigeria. Other guest speakers were Dr Ogunrin of College of Medicine, University of Benin in the Niger delta; Dr Achor Ju of the Federal Neuropsychiatric Hospital Enugu; and Dr W Igwe, a pediatric neurologist from Nnamdi Azikiwe University Teaching Hospital Nnewi, in Anambra State of Nigeria. Sixteen papers and three lectures were delivered on the various aspects of epilepsy care. The Conference was preceded by public epilepsy awareness both in schools and on radio with great responses from the community. The Conference ended with the National Congress and the following resolutions were taken:

- The association's name was changed from ILAE Nigeria Chapter to Nigerian League Against Epilepsy (NLAE).
- A commission on research was set up to come up with an instrument for epilepsy interview for health caregivers. The aim is to harmonize the work of different researchers so that data could be compared.
- Two NLAE merit awards were created. One award for distinguished members of the Association or Society with regards to epilepsy care and a second award for any research student who engages in epilepsy research.

Summary of Activities in Relation to Global Campaign in 2011 and 2012

Other important events of 2012 were the various awareness programs and community work of Prof MC Nwosu and his team at Ukpo in Dunukofia in Anambra state, the awareness program of Mrs Asemota AO. She founded the Angie Epilepsy group after her child developed epilepsy and her marriage broke up because of the child's illness. She has held several meetings where basic but important issues about epilepsy were treated by our members who act as her resource persons. She presented a paper at the Nigeria Society of Neurological Sciences at Oshogbo in 2012.

Educational Activities

Activities so far:

- Four epilepsy radio programs since 2009
- Epilepsy School Program reaching close to 2,500 students
- Conferences, scientific meetings and workshops. More than 150 participants attended these conferences with more than 45 research papers presented
- Two EEG training sessions. One session of epidemiological research
- Individual efforts have been encouraged leading to the setting up of Ukpo Epilepsy Center, Mgbowo research center and Angie Epilepsy Program Advocacy
- NLAE is working together with teaching hospitals and specialist hospitals to enhance epilepsy care.

Future Plans

- 2013 Congress
- Village/Town hall awareness meetings
- 2013 radio and school programs.

Officer Election Date

2014

Report By

Dr Ezeala-Adikaibe Birinus

EPILEPSY ASSOCIATION OF PAKISTAN

Summary of Activities in 2011 and 2012:

In Pakistan, a public awareness campaign for epilepsy has been ongoing for more than two decades, with most activity since 2001. Various projects have been undertaken and new ones are being developed to achieve the main objective of "changing the nation's mind-set towards epilepsy, the disorder and people with epilepsy (PWE); and decreasing the treatment gap."

In 2011-2012 the main focus was on epilepsy awareness via electronic media. Comprehensive Epilepsy Control Program of Pakistan produced an epilepsy awareness documentary to educate the masses about the nature of the disorder, its treatability and reiterating the fact that the majority of PWE are 'normal' human beings. Abdul Sattar Edhi, a social worker par excellence of international repute (many times more than 'Mother Teresa' because of the diversity and quantum of his humanitarian services for more than 60 years), who is known to every Pakistani, and a patient, Ms Sulakhshana Laloo Kamley, talk about their epilepsy and how it has not affected their lives. This is a definite morale booster for the epilepsy patients and their caretakers. All information is conveyed through a collection of bulleted messages to keep the duration brief (five minutes) in view of the limited attention span of an average TV viewer (with ~100 channels, they keep on surfing) and to reduce the telecast costs. This documentary has been produced with narration in Urdu, English, Sindhi, Pushto and Balochi.

Paid telecasts on popular satellite television channels in the national and regional languages are also being done. The documentary is being telecast twice a day for three months on each channel. To date, the documentary has been aired on three channels in three of the four provincial languages. This documentary has been exhibited at the ILAE Congress booth. The production of this documentary and paid telecasts has been sponsored by Novartis Pharma (Pakistan) Ltd.

Patient Management at the NGO-run National Epilepsy Centre (NEC), Karachi, continues where patients are supplied monthly medicine at a token cost (~2 percent of the actual cost; the remaining being born by a philanthropic family) and EEG done at highly subsidized rates. The radiology department of the public sector hospital provides the facility of MRI & CT at subsidized rates. All specialists at NEC extend voluntary services and ensure strict compliance. On 31 December 2012 the number of registered NEC patients was 5,315.

Educational Activities

An ASEPA Teaching Course on Focal Epilepsy was held in Karachi, Pakistan, 29-30 January 2011. International speakers Drs Y Inoue, R Neshige, and Y Koide from Japan and some local speakers spoke on various aspects of focal epilepsy. The workshop was followed by four-day EEG training workshops by Dr R Neshige held in Karachi and Lahore. These trainings were highly appreciated by the participants who have shown a desire to attend further such workshops. The number of participants was as follows: Karachi focal epilepsy workshop – 110; Karachi EEG workshop – 65; Lahore EEG workshop – 90.

ASEPA-ASNA EEG Certificate examination – Part One was held on 30 January under supervision of Dr Yushi Inoue; 18 candidates took this exam.

A handbook on epilepsy management for general practitioners with a CD showing various seizure types was distributed under the aegis of Comprehensive Epilepsy Control Program of Pakistan among primary care physicians.

Future Plans

The paid telecasts of the epilepsy awareness documentary on satellite television channels shall continue for our message to penetrate into most households and reach the maximum population in Pakistan. Workshops for primary care physicians in various cities and towns are being planned. An epilepsy update symposium for specialists with possible foreign speakers is also on the agenda.

Officer Election

June 2012

Report By

Prof Shaukat Ali, President

PHILIPPINE LEAGUE AGAINST EPILEPSY (PLAE)

Summary of Activities in 2011 and 2012

Opening the new secretariat. The need to find a more spacious, efficient and strategically located administrative office emerged during the revisiting of the Mission and Vision of the PLAE in 2008 in response to the clamor for better communications and increasing participation among our members. We have an organization email address where members can write about their concerns:

plaesecretariat@yahoo.com. The website, www.plae.org.ph is continuously being updated with

the help of Pfizer. With the secretariat we have received inquiries about our projects from media, patients and potential members of the ILAE. We have also updated our Roster of Members, membership status, dues and financial reports. We have an active roster of 154 members. We also have updated registration and financial reports with the Securities and Exchange Commission.

Recommitment workshop of the Epilepsy Campaign volunteers. When the Epilepsy Campaign was launched in 2001, we asked for doctor volunteers who would implement the awareness campaign in Manila and in other provinces nationwide. We called them PAVES (Public Awareness Volunteers for Epilepsy)-BRIDGES (Bridging Referrals in the Delivery of Grassroots Epilepsy Services). We started with only 20 volunteers who committed 1) to holding a free epilepsy clinic for indigent patients in their own communities, and 2) to holding at least two lay forums in their communities or hospitals every year. Over the years, the number of volunteers has increased to forty. In July 2012 we convened the PAVES for a day of recommitment, updating and planning for future projects of the PLAE. We awarded plaques for appreciation for our outstanding volunteers who initiated and implemented innovative awareness programs and rendered service "beyond the call of duty."

Epilepsy Surgery Study Group. This group was organized in April 2010 to address the problem of underutilization of epilepsy surgery as a mode of treatment in refractory epilepsy in the country. In spite of the availability of four comprehensive epilepsy centers in Manila with several epileptologists and epilepsy surgeons trained in the United States and Australia, the referral rates are still low. The objective of the group is 1) to promote awareness of epilepsy surgery as a standard form of treatment for refractory epilepsy, 2) to address factors that contribute to its underutilization, and 3) to develop a locally relevant algorithm for referrals of refractory epilepsy cases to epilepsy centers.

The 1st Epilepsy Surgery Forum entitled, "Epilepsy Surgery in the Philippines: Overcoming Challenges in a Developing Country" was held on 6 September 2010 and was attended by 106 participants. Proceedings from the forum were presented at the midyear convention of the Philippine Neurological Association on 3 June 2011. The study group intends to have the proceedings published as a guideline. We have also started quarterly Epilepsy Surgery meetings that will be rotated in different epilepsy centers in Manila.

The National Epilepsy Registry. Last year, the Partners In Epilepsy database software was made available for the exclusive use of PLAE by Jansen for the National

Epilepsy Registry. We developed the research protocol, informed consent and memorandum of agreement between Jansen and PLAE. They also devised a mechanism for securing data in each clinic and hospital, and then transferred to a central database. Research coordinators from the training hospitals in Manila attended the orientation for the launching of the Registry. The fund for the Registry was already prepared for the purchase of computers. A technical grant was donated by Janssen. However, due to some last minute problems with the coding of the software copies, the launching of the Registry has been delayed. Once this is resolved, the Registry will be launched early next year.

Epilepsy Awareness Week 2010. The 9th Epilepsy Awareness Week was celebrated from 5-12 September 2010 with the theme "Pushing Boundaries in Epilepsy." This encompassed our initiatives to do something that has not been done before, to talk about things that have not been tackled in the past, and to go to places where we have never been before. The 1st Epilepsy Surgery Forum was held as described above. Then we decided to push further geographically, going south to Butuan in Mindanao for the National Epilepsy Camp. The regular activities done yearly, like the lay forum and the media campaign on TV and print media were carried out. The Epilepsy Exemplar awards ceremony was held in the GSK Auditorium during Epilepsy Week in September 2010. Three awardees with epilepsy were given special recognition, among them a teacher/guidance counselor from La Union, a math teacher from Manila, and a student from Nueva Ecija.

We also continued the Epilepsy School Caravan Project which was launched in the last quarter of 2009. With more confidence to implement the innovative storytelling-dance module on epilepsy after the initial salvo, our volunteers continued to reach out to many grade schools around the country, reaching 108 schools by the end of Epilepsy Week 2010.

Reorganization of the EAAI. The Epilepsy Awareness and Advocacy Incorporated (national lay support group) elected its new officers December 2010. They took charge of organizing the 3rd National Lay Symposium entitled "Epilepsy ay Huwag Ibalewala, Kinabukasan ay Ihanda" which was held on 14 September 2011. They maintain a Facebook account that allows patients to interact regarding their experiences and seizures. They are assisting in the organization of the Epilepsy and Society Program for the Asian Oceanian Epilepsy Congress in Manila in 2012. The PLAE continues to guide and support them as they take their first few steps to becoming a truly national organization of persons with epilepsy.

Ketogenic Diet Study Group. The Ketogenic Diet Study Group was organized 1 April 2011. Their objective is to explore the usefulness, feasibility and applicability of the Ketogenic Diet in the Philippines. They have met a few times to formulate a protocol which is affordable and applicable to Filipino patients (i.e. powdered coconut milk) who might benefit from the diet. A Ketogenic Diet Registry form and a Symposium are being considered as future plans.

The Epilepsy Manager Project (EMP). In April 2010, three trainees of the Epilepsy Manager project from remote areas of Iloilo in Panay Island graduated from this one-year mentoring program on epilepsy. They have returned to their communities. We hope their Epilepsy Clinics will continue.

For 2011-2012, the Epilepsy Manager Project received sponsorships for three possible areas for training general practitioners or municipal health officers. Initially the EMP was scheduled for Naga, Camarines Sur, Misamis Oriental and Lanao del Norte. At last, we have gone over to Mindanao, where it is most needed! We are training 10 rural medical doctors this year. Twenty-six dedicated PLAE members go in pairs and take turns in visiting the epilepsy clinics and mentoring the doctors monthly in ten remote areas this year.

8th Asian Oceanian Epilepsy Congress in 2012. The highlight of our term is the privilege to be chosen as the host. Several visits by the ILAE Convention staff and by the International Scientific Committee and IBE were made in preparation for the big Congress on 22-25 March 2012. The PLAE will participate in the Scientific Program by sharing in a significant number of the lectures given by our local experts.

10th National Epilepsy Awareness Week from 3-10 September 2011 was opened by a Negosyo Fair, a livelihood training program on 3 September for epilepsy patients and their families. The day was capped by a dinner fellowship, "A Decade of Making a Difference," at the Club Filipino to mark the 10th anniversary of the National Epilepsy Campaign, and to launch the new theme for National Epilepsy Awareness Week, "Seize Epilepsy. Seize Control. Seize Life." Epilepsy seminars and Epilepsy School caravans were conducted in several hospitals and schools in Manila, Cagayan, Tacloban, Baguio, Lucena, Mindoro Occidental during the first week of September.

6th National Epilepsy Congress. Our theme for this year is "Epilepsy, Mind and Behavior." This year's Congress is exceptional because it is the first time we are having four international speakers, including no less than the president of the International League Against Epilepsy himself, Dr Solomon Moshé, Michel Baulac, Marco Mula and Deepak Gil. An expected 300 delegates will attend this Congress.

POLISH SOCIETY OF EPILEPTOLOGY

Publications

Contribution to textbook (in Polish) "Women and Epilepsy" (at press).

Meetings

In 2011: XXIII Conference on Epilepsy organized by Polish Society on Epileptology (PSE), Warsaw, 19-21 May with 400 participants

In 2010: XXIV Conference on Epilepsy organized by Polish Society on Epileptology, Warsaw, 17-19 May with 400 participants

National experts on various fields of epilepsy were invited to give lectures. The topics covered were: epilepsy and pregnancy, video-EEG diagnostic values in different types of epileptic syndromes and non-epileptic events. A very important session was devoted to quality of life problems, especially the impact of communication between the medical doctor and patient.

Summary of Activities in 2010 and 2011

- 5th Baltic Sea Summer School on Epilepsy, Sopot, 19-24 June 2011. It was a great challenge for the PSE to help organize a successful and memorable course for 44 participants from 17 countries
- Many public lectures and discussion group meetings have been organized with neurologists on public health awareness
- Organization of Central Europe Epilepsy Experts Working Group Meeting January 2011 – Presentations and discussion on epilepsy patient management in Central European countries.

Summary of Activities in Relation to Global Campaign in 2010 and 2011

Patronizing and supporting the Valentine Epilepsy Days every year on 14 February. 'Notice me' is the national campaign of different patient associations from all over Poland. It was launched in 2009 in Warsaw. In 2011 the campaign gained a new event — Nordic Walking March. The motto of the March was "Notice me walk healthy."

An important part of our activities in 2010 and 2011 are contacts with the Ministry of Health and National Health Fund. The main problem was reimbursement for patients for new AEDs. Finally, as of January 2012 Levetiracetam is free for patients with epilepsy.

Educational Activities

- Regular educational courses and workshops on epilepsy in Poland
- Working group on epilepsy and pregnancy, on quality of life, with the elaboration and validation of an original questionnaire for patients and caregivers
- Working group on videos, with the collection of informative videos on different seizure types and elaboration of appropriate tools for the didactic presentation of the material.

Activities in Conjunction with Local IBE Affiliate

Continue helping the organization by providing an umbrella function and coordinating the local societies. Patronizing the Valentine Epilepsy Days. At the moment in Poland, there exists 14 organizations of patients (nine are district Chapters of Polish People Suffering from Epilepsy established in 1985).

Future Plans

- To continue the regular educational courses
- To elaborate the new standards of quality control, to epilepsy care in Poland
- There will be a reunion Polish School of Epilepsy
- We are preparing to produce a national guideline on management of epilepsy in adults and children in conjunction with the Polish Neurological Society.

Officer Election Date 2014

Reported By

Joanna Jędrzejczak

PORTUGUESE LEAGUE AGAINST EPILEPSY

Summary of Activities in 2011 and 2012

The Iberian Annual Meeting occurred in Malaga in October 2011. The next Iberian meeting was in October 2012, in the city of Porto. The 23rd National Epilepsy meeting took place in Lisbon on 18-19 March 2011. The 24th National Epilepsy Meeting took place in March 2012, in Coimbra. Four epilepsy surgery forums, with participants from all Portuguese centers, were also organized to discuss several clinical cases, and took place in March 2011, November 2011, March 2012 and November 2012. The 6th Migrating Course occurred in Porto in June 2012. This course was organized in close collaboration with the European Commission Affairs of the ILAE.

Summary of Activities in Relation to Global Campaign in 2011 and 2012

The Portuguese League launched a national program, that was up and running in October 2011 and will carry on until March 2013; a set of educational videos about seizures was produced; there was a presentation of a multimedia exhibition that will occur throughout 2013. With the approval of the Written Declaration on Epilepsy by the European Parliament, the Portuguese League scheduled a set of measures to promote a better understanding of epilepsy among politicians.

Educational Activities

The Portuguese League in collaboration with the patients association launched a national program, which was presented for the first time in March 2012, at the National Epilepsy Meeting, during a ceremony that various politicians, sports people and artists attended. The 6th Migrating Course occurred in Porto in June 2012. This course was organized in close collaboration with the European Commission Affairs of the ILAE. A great number of photos were taken with several sports people and patients, which are exhibited with the Stand Up for Epilepsy initiative.

Activities in Conjunction with Local IBE Affiliate

The Portuguese League in collaboration with the patients association launched a national program, which was presented for the first time in March 2012, at the National Epilepsy Meeting, during a ceremony that various politicians, sports people and artists attended. It was up and running in October 2011 and will carry on until March 2013; a set of educational videos about seizures was produced; there was a presentation of a multimedia exhibition, that will occur throughout 2013.

Future Plans

The 25th National Epilepsy Meeting, will take place 8-9 March 2013, in Porto. An epilepsy surgery forum, with participants from all Portuguese centers, will occur on 7 March 2013 to discuss several clinical cases.

Report By

Francisco Sales

QATAR NEUROLOGY AND QATAR LEAGUE AGAINST EPILEPSY (QLAE)

Publications

Al Hail, Hassan. Epidemiology and Etiology of Intractable Epilepsy in Qatar, Qatar Medical Journal volume13/number1; June 2004, pp. 11-13. Regional neurology journals: 2-Deleu D, Mesraoua B, Al Hail H, Dsouza A, Mahmoud HA.

Summary of Activities in 2011 and 2012

- Qatar Annual Neurology and Epilepsy meeting February 2011 and 2012
- Five neurologists from Hamad Hospital attended the 28th International Epilepsy Congress, 29 to 1 October 2012 in London
- Recently, two neurologists had attended the Asia epilepsy conference at the 2011 China Epilepsy Congress.

Summary of Activities in Relation to Global Campaign in 2011 and 2012

Educational Activities:

- Training workshop on Electroencephalography for young neurologists was held in the Department of Neurology in Hamad General Hospital
- Regular training for medical students form Weil Cornell Medical Faculty in Doha
- Participation with epilepsy cases in the Hospital weekly Neurology Grand Round.

Educational Activities

Expert exchange programs for internationally known neurologists and epileptologists as visiting consultants for patient care and lecture presentations. Last year we invited Prof Dr Wisser from Switzerland and Prof Dr E Perucca from Italy and many other neurologists from the Region to the 6th Qatar Regional Neurology Conference. In February 2011, different international and national speakers will be focusing on epilepsy and other neurology topics in the 6th Qatar Neurology Conference.

- Published small books on epilepsy written for the public in Arabic language explaining different aspects of epilepsy symptoms, diagnosis and treatment. The first book (about 100 pages) was written by Dr Hassan Al Hail and the second book (about 200 pages) was written by Dr M Fawzi, a pediatric neurologist
- Several education media programs about epilepsy were made for local Qatar TV and local newspapers
- An Intranet site was established in our Hospital website. The website http://qatarneuroscience. webs.com/; focuses on epilepsy education and other aspects

 Our neurology department staff members have attended and participated in many regional, local and international epilepsy conferences.

Activities in Conjunction with Local IBE Affiliate

The Qatar League Against Epilepsy (QLAE) was established in 1995 and since that time is the Qatar Chapter of the International League Against Epilepsy (ILAE) and the International Bureau of Epilepsy. During the recent years QLAE had initiated several educational and Congress activities. Several local and regional (Gulf Region) neurology and epilepsy conferences took place.

Future Plans

Working to get approval and support to have East Med Epilepsy Conference in 5-7 October 2013

- Upcoming 7th Annual Qatar Epilepsy meeting 15-17 February 2013
- Upcoming annual pediatric epilepsy training PET1 and PET2 28 February to 3 March 2013. Working to get comprehensive epilepsy center
- Increase our staff physician and EEG technologist numbers
- Several works for publication are in progress:
 Epidemiology of Epilepsy in Qatar, Knowledge and awareness of epilepsy in epilepsy patients and their families
- Get approval for a national epilepsy day.

Officer Election Date

March 2013

Report By

Dr Hassan Al Hail and Dr Tage eldin Sokrab

SAUDI CHAPTER OF EPILEPSY

Publications

Website: www.saudiepilepsysociety.org Journal: Neuroscience Journal

Objectives

- 1. Ensure the official presence of Saudi delegates in scientific and administrative meetings of ILAE.
- 2. Supervision of scientific and academic activities related to epilepsy in Saudi Arabia.
- 3. Coordinate regular scientific meetings of the Saudi Chapter of Epilepsy in different regions of Saudi Arabia.
- 4. Supervision of epilepsy training. Supervision of medical and technical EEG training.

Saudi Chapter of Epilepsy Summary of Activities in 2011 and 2012

- 1. Amalgamation of Saudi Epilepsy Society (SES) and Saudi Chapter of Epilepsy (SCE).
- 2. Updated the SES SCE bylaws.
- 3. Provide information materials about epilepsy (available at the SES website).
- 4. Activate SES website.
- Outline the bylaws about Epilepsy and Driving in collaboration with the Saudi Traffic and Safety Department (still in process).

The Saudi Epilepsy Society has formed ten Committees to carry out strategic planning and to improve the level of epilepsy education.

- 1. Research, Education and Scientific Committee
- 2. Epilepsy Surgery and Neurosurgery Committee
- 3. Child Epilepsy Committee
- 4. Psychiatry and Neuropsychiatry Committee
- 5. Adult Epilepsy Committee
- 6. Neurophysiology Committee
- 7. Neuropsychology Committee
- 8. Website Committee
- 9. Media Committee

Saudi Epilepsy Society Summary of Activities in 2011 and 2012

- 1st Annual Saudi Epilepsy Society Symposium (Endorsed by the ILAE-CEMA)
 Riyadh, 11-13 January 2011
- Ketogenic Diet in the Management of Intractable Epilepsy Dammam, 23 February 2011
- Epilepsy and Driving (Endorsed by the ILAE-CEMA) Riyadh, 22-23 May 2012

Epilepsy and Driving in collaboration with Saudi Traffic and Safety Department and major hospitals in Saudi Arabia, Saudi Commission for Health Specialties and ILAE-CEMA

Venue: Intercontinental Hotel, Riyadh Meeting Objectives:

- Increase awareness about epilepsy and driving
- Discuss motor vehicle accidents resulting from seizures occurred during driving
- Discuss the international Bylaws regarding epilepsy and driving
- Discuss the need for establishing Bylaws in Saudi Arabia regarding epilepsy and driving
- Discuss the relationship between the insurance companies and the drivers who suffer from epilepsy
- Participation in Saudi Critical Care Society Symposium Riyadh, 23-27 April 2011

- 19th Annual Saudi Neurosciences Symposium Dammam, 22-24 November 2011
- 2nd Annual Saudi Epilepsy Society Symposium Done in collaboration with Saudi Commission for Health Specialties, King Abdulaziz University and ILAE-CEMA

Date: 12-14 November 2012

Venue: Crowne Plaza, Jeddah

This symposium represents a timely proactive response to the need for greater understanding of these disorders. State of the art lectures, updated presentations, workshops and panel discussions will be included in several epilepsy disciplines including clinical adult and pediatric neurology, neurosurgery, neuroradiology, neuropsychology, psychiatry, and clinical neurophysiology. These overlapping areas are generally considered difficult and are not well covered in undergraduate and postgraduate neurology training. The symposium presents a unique opportunity to address important disorders both at the basic and advanced levels. Topics will be presented by a number of distinguished international and national faculty members. We are confident that the presentations will impress, inform, and update our knowledge in these fields.

Target Audience: Physicians, Residents-in-Training, Nurses, Technologists, Students and Allied Health Workers

 7th Annual Eastern Province Epilepsy Symposium 10-11 April 2013 at the Sofitel Hotel – Dammam. Topics include: Mesial Temporal Lobe Epilepsy; EEG course; Epilepsy awareness day in Arabic.

Election of Officers

February or March 2013

SLOVENIAN LEAGUE AGAINST EPILEPSY

Slovenian Epilepsy Association combines both Slovenian ILAE and IBE Board Committee members. This means that both work united in the care for professional development of epileptology in Slovenia, as well as to improve the quality of life of people with epilepsy, their families and friends. Most campaigns were organized by pulling together lay people and experts in the field of epileptology.

Completed Activities in 2011

• 7th Postgraduate school of practical epileptology with lectures and hands—on clinical seminars according to principles of the original French school with international cooperation (Ecole Pratique Jean Bancaud; French - German-Czech - English - Slovenian): Neuropsychiatry of epilepsy; three-day program

- Gained support of all Slovenian MPs for the European Declaration on Epilepsy
- 1st European Epilepsy Day (organization of press conference well attended by journalists of various television and radio programs; newspaper and magazine articles more than 20)
- Education support: Epilepsy Center Cleveland Clinic – one MD sent
- Lectures for patients, relatives, teachers and general public (11 lectures in schools and kindergartens)
- Advice for individuals and groups, help-line telephone (EPITEL) anonymously or in person
- Support program for patients treated abroad (since surgery is carried out abroad, our Association has a program for escort interpreters – usually medical students) with financial and psychosocial support for families – 13 times
- Two meetings with parents of children with newly diagnosed epilepsy
- Printed booklet "My child has epilepsy"; and reprint of leaflet "First aid in epileptic seizure"
- Four editions of Association newsletter "Žarišče"
- Coordination of five self-help groups
- Preparing the ground for new self-help groups
- 20th anniversary of self-help group, Koper, with round table on "Meeting employer's fears and concerns in employment of people with epilepsy"
- Cooperation with other patient organizations and associations
- Participation in Patient Council of the University Medical Centre in Ljubljana
- Preparation for the 2nd European Epilepsy Day
- Two public forums in different parts of Slovenia
- Meetings of adolescents and young adults with epilepsy
- Public relations and media exposure of problems with comprehensive treatment of adults with epilepsy in Slovenia.

Completed Activities in 2012

- 8th postgraduate school of practical epileptology with lectures and hands-on clinical seminars according to principles of the original French school with international cooperation (Ecole Pratique Jean Bancaud French – German – Czech – English – Slovenian): Functional imaging and new approaches for the diagnosis of epilepsy; three day program
- 2nd European Epilepsy Day (organization of press conference attended by journalists of various television and radio programs; more than 80 newspaper and magazine articles)
- Attendance of Slovenian MPs at the European Epilepsy Day event in the European Parliament

- Education support: Epilepsy Center Cleveland Clinic – two MDs and one EEG technician sent
- Sixteen lectures for patients, relatives, teachers and general public
- Psychosocial help-line telephone (EPITEL) each Thursday 4-7 p.m.
- Program for patients treated abroad (our Association has a program for escort interpreters – usually medical students) and financial as well as social support for families – 19 times
- Two meetings with parents of children with newly diagnosed epilepsy
- Printed publications include: leaflets and booklets "Epilepsy in the elderly"; reprint of leaflet "Epilepsy and sport"
- Four editions of Association newsletter "Žarišče."
- Coordination of six self-help groups
- Kindling of new self-help groups
- 20th anniversary of self-help group, Maribor, with lecture on juvenile myoclonic epilepsy
- Cooperation with other patient organizations and associations
- Participation in Patient Council of the University Medical Centre in Ljubljana
- Preparation for the 3rd European Epilepsy Day
- Two public forums in different parts of Slovenia
- Meeting of adults with epilepsy after surgical treatment
- Public relations with media exposure of problems of comprehensive treatment of adults with epilepsy in Slovenia
- Started Association website containing all relevant information about our activities
- Preparations for 13th European IBE Conference "Epilepsy and Society," 28-30 August in Ljubljana, Slovenia and 9th postgraduate practical epileptology school.

EPILEPSY SOCIETY OF SOUTH AFRICA

Meeting

9 June 2012

Summary of Activities in 2011 and 2012

A national two-day epilepsy teaching and update meeting was held for the fifth successive year. This attracted 150 neurologists and was well received.

Summary of Activities in Relation to Global Campaign in 2011 and 2012

Two of our members presented papers at the inaugural Africa Epilepsy Congress held in Nairobi in June 2012.

Good personal contacts were made, which we hope will facilitate collaboration within Africa.

Educational Activities

In Cape Town, a weekly multi-disciplinary clinical meeting devoted to epilepsy is held.

Activities in Conjunction with Local IBE Affiliate

Two of our members serve on the Committee of Epilepsy South Africa, which is the national IBE. Their organization holds an annual epilepsy awareness week to which we contribute speakers.

Future Plans

- To increase our collaborative efforts in the field of epilepsy, particularly in the sub-Saharan region of Africa.
- 2. To establish a website which will be of value both to the medical community and to the public.

Officer Election Date

15 March 2013

Report By

Prof Roland Eastman

SWEDISH EPILEPSY SOCIETY

Summary of Activities in 2011 and 2012

Drawing up guidelines for epilepsy care and a national epilepsy registry

Summary of Activities in Relation to Global Campaign in 2011 and 2012

Participation in photo exhibition, London 2012

Educational Activities

Courses and workshops: Different aspects of Refractory Epilepsy; Dravet syndrome: from genes to ion channels; Bridging basic and clinical epilepsy; Standardized Computer Organized Reporting of EEG (SCORE); Evidence-based epilepsy care; Neonatal CFM-monitoring; and DBS for epilepsy

Activities in Conjunction with Local IBE Affiliate

- European Parliament Written Declaration on Epilepsy: work on Swedish members of the European Parliament
- Epilepsy Day

Future Plans

- National epilepsy register
- Preparing for ECE in Stockholm 2014
- Educational activities for epilepsy nurses
- Educational course on Tuberous Sclerosis
- Educational course for epilepsy team

Officer Election Date

9 November 2012

Report By

Eva Kumlien

SWISS LEAGUE AGAINST EPILEPSY

Summary of Activities in 2011 and 2012 Publications

- Journal Epileptologie (Epileptology), publication four times a year, 50-70 pages each, with information about new developments in epilepsy research and treatment (for professionals, 1,500 copies)
- Newsletter Epilepsie News, publication three times a year, four pages each, with information about the activities of the League and about epilepsy (for laypersons, about 22,000 copies in German, about 8,000 copies in French).

2011

- Brochure on "Prizes and Grants in Epileptology" in German (350 copies)
- Annual report in German and French (1,000 copies)
- Brochure on events of the Swiss League Against Epilepsy in German and French (3,000 copies)
- Monthly electronic newsletter (more than 10,000 German-speaking recipients and 3,600 French-speaking recipients).

2012

- Brochure on "Prizes and Grants in Epileptology" in German (100 copies)
- Three new information leaflets on Vagus Nerve Stimulation, Compliance, and on Ketogenic Diet in German (8,000 copies) and French (2,000 copies)
- Annual report in German and French (1,100 copies)
- Brochure on events of the Swiss League Against Epilepsy in German and French (2,500 copies)
- Monthly electronic newsletter (more than 10,000 German-speaking recipients and 3,600 Frenchspeaking recipients)

 Special edition of the journal Epileptology, publication of the Survey of Public Attitudes towards Epilepsy in Switzerland.

Meetings

- 7th Joint Meeting of the German, Austrian and Swiss Chapters of the International League Against Epilepsy (ILAE) in Graz, Austria, 1-4 June 2012
- Annual Congress of the Swiss League Against Epilepsy, the Swiss Society of Clinical Neurophysiology and the Swiss Neurological, in Lugano, 3-5 May 2011.

Participation at different meetings, Congresses and courses including: "Journée Romande d'épileptologie" in Lausanne; Multi-professional Symposium in Zurich; Symposiums on Epilepsy in Zurich, Basel and Bern

2011

- Three annual events in different cities, for laymen, with several lectures by epilepsy experts. Main Topic: "Life with Epilepsy"
- Three annual events in different cities, for professionals, with several lectures by epilepsy experts
- TV-Spot "Together" for the German part of Swiss
- Awarded a grant (CHF 20'000) for the most promising research study in Switzerland in the field of epileptology
- Awarded Franco Vassella, Bern, with the Tissot medal, offered by the Swiss League Against Epilepsy
- Awarded of the "Hauptmann-Preis" (10.000 Euros) in Graz, Austria
- Publication of a Position Statement of the Swiss League Against Epilepsy: Use of Generic Antiepileptic in the Treatment of Epilepsy
- Social Research: Survey of Public Attitudes towards Epilepsy in Switzerland.

2012

- Three annual events in different cities, for laypersons, with several lectures hold by epilepsy experts. Main Topic: "Life with Epilepsy"
- Three annual events in different cities, for professionals, with several lectures hold by epilepsy experts
- Awarding of a grant (CHF 20'000) for the most promising research study in Switzerland in the field of epileptology

 Campaign with Yann Sommer, goalkeeper of FC Basel, Swiss Champion in 2012: DVD production, photos and media, participation in the exhibition "Stand up for Epilepsy" of the 10th European Congress on Epileptology, in London, September.

Summary of Activities in Relation to Global Campaign in 2011 and 2012

2011: Main event on the "Day of Epilepsy," 5 October, in Zurich. Topic: "Epilepsy and Social Media." Open to laypersons and professionals accompanied by a media campaign.

2012: Main event on the "Day of Epilepsy," 4 October, in St Gallen Topic: "Epilepsy and Mobility." Open to laypersons and professionals accompanied by a media campaian.

Educational Activities

2011: Lectures for the staff of the pharmaceutical industry

2012: Lectures for the staff of the pharmaceutical industry

Activities in Conjunction with Local IBE Affiliate

2011: Special day for patients and their relatives. Topic: "Epilepsy and Hormones"

2012: Special day for patients and their relatives. Topic: "Side Effects of Antiepileptic Medicaments"

Future Plans

Publication of the Report Epilepsy in Switzerland

Officer Election Date

Spring 2013

Report By

Daniela Erb, Secretary-General

TAIWAN EPILEPSY SOCIETY (TES)

Publications

- 1. Taiwan Epilepsy Guidelines
- 2. Archives of Taiwan Epilepsy Society
- 3. Consensus of Chinese Translation of Epilepsy Terminology

Meeting

 9 April 2011 Annual Meeting of Taiwan Epilepsy Society

2. 14 April 2012 Annual Meeting of Taiwan Epilepsy Society

Summary of Activities in 2011 and 2012

The years 2011 and 2012 were periods of remarkable developments both domestically and internationally for Taiwan Epilepsy Society (TES).

- The TES held its Annual Meeting in April 2011 and 2012 (Taipei). Both meetings were very well attended and provided many thought-provoking sessions.
- 2. The year 2011 also marked the change of office for the TES Board of Directors. The new Board was elected at the Annual Meeting of TES held on 9 April 2011, and Prof Tony Wu was elected as president of TES.
- 3. Completed the first version of "Taiwan Epilepsy Guidelines" in 2012.
- 4. Compiled "Archives of Taiwan Epilepsy Society" in 2012.
- Delegates from six Chinese-speaking areas (China, Hong Kong, Macau, Malaysia, Singapore, and Taiwan) signed consensus agreement on Chinese translation of epilepsy terminology on 25 November 2011 at Xiamen.
- 6. Co-organization of the "6th Antiepileptic Drug Treatment Conference" (with Asian Epilepsy Academy, ASEPA).
- 7. Three research awards are given annually, including "Young Investigators Travel Award," "Epilepsy Best Paper Award," and "Epilepsy Research Award"

Summary of Activities in Relation to Global Campaign in 2011 and 2012

Stand Up For Epilepsy – Taiwan Epilepsy Sports Day – To support the "Stand Up For Epilepsy" project of ILAE and encourage people with epilepsy to do outdoor activities, TES organized an exciting and innovative event "Taiwan Epilepsy Sports Day" on 12 May 2012. Over 250 people with epilepsy, their families, and doctors in Taiwan took part in a running event with Taiwanese ultra-marathon champion Kevin Lin in the square of National Chiang Kai-shek Memorial Hall, Taipei. The major aim is to encourage patients with epilepsy to actively participate in sport and physical activity, and urge the right of doing physical exercise for people with epilepsy. The TES specifically asked swimming pool operators to take off the regulation that "people with epilepsy are prohibited from entering the swimming pools." A well-designed gift, "Seizure First Aids Tips" necklace, was presented to each patient. Wearing this necklace during exercise may provide urgent safety and supportive information if seizure happened. The event ended with a renewed enthusiasm to "stand up for epilepsy" together with a

fresh understanding that people with epilepsy, like athletes themselves, can be inspired to achieve their goals and lead active lives.

Educational Activities

- "6th Antiepileptic Drug Treatment Conference" (co-organized with Asian Epilepsy Academy, ASEPA) on 3 July 2011 in Taipei.
- 2. "Young-Star Epilepsy Training Program" was delivered once a year (6 November 2011 and 21 October 2012 in Taipei). This program was addressed to residents in neurology/neurosurgery/pediatric neurology, especially for those who just passed the Neurology Board Examination. The courses were limited to a maximum of 130 participants each year and were fully booked.
- 3. "Continuing Medical Education Program: Syndromic Diagnosis of Epilepsy" was conducted three times in Taiwan in 2012.
- 4. "EEG Education Courses" were conducted three times each year in Taiwan.
- "Introduction and Managing Patients with Epilepsy" was conducted three times in 2012, in order to provide comprehensive epilepsy education to nursing professionals.
- "Introduction of Epilepsy" was conducted three times each year. This course was addressed to school staffs and nurses, in order to raise awareness, communication and education on the theme of epilepsy. More than 1,000 teachers or school nurses attend the courses.

Activities in Conjunction with Local IBE Affiliate

See above Taiwan Epilepsy Sports Day

Future Plans

- 1. The Taiwan Epilepsy Society Annual Meeting will be held in Taipei in 27-28 April 2013.
- 2. Two Task Forces on "Neuromodulation Therapy for Epilepsy" and "Epidemiology Studies of Epilepsy in Taiwan" will be formed, in order to gather and integrate expert and members who are interesting in these two fields.

Officer Election Date

April 2013

Report By

Siew-Na Lim, MD, PhD, Secretary-General

TURKISH LEAGUE AGAINST EPILEPSY

Publications

Epilepsi journal published three times a year with two supplements

Meeting

8th National Epilepsy Congress

Summary of Activities in 2011 and 2012

- 1. Monthly meetings: held in Kalyon Otel, Sultanahmet, Istanbul.
 - a. 27 January 2012 Panayiotopoulos Syndrome Prof Aysin Dervent MD
 - b. 24 February 2012 Epilepsy and Depression Prof Marco Mula MD
 - c. 30 March 2012 Status Epilepticus Prof Reetta Kalvianen MD
 - d. 20 April 2012 Case presentations Workshop
 - e. 9 November 2012 Intractable epilepsy: A role of multidrug resistance proteins and transporters, Prof Heidrun Potschka
- 8th National Epilepsy Congress held 24-27 May 2012 in Bodrum Mugla.
 - a. over 400 Congress attendees
 - b. Half-day EEG teaching course with nine lectures, four satellite symposia, 11 main sessions, 83 presentations (both poster and platform)
- 3. Epilepsi journal of Turkish League Against Epilepsy. Published three times during the year with two supplements (one for the Congress abstract and one on epilepsy surgery).

Educational Activities

EEG teaching course that was held with the National Epilepsy Congress

Future Plans

- 11 January 2013, Anti-neuronal antibodies in epilepsy and encephalitis, Assoc Prof Erdem Tüzün, MD
- 25 January 2013, Genetics of epilepsy- Istanbul University experience, Prof Ugur Ozbek, MD, PhD
- 22 February 2013, Teratogenesis and epilepsy, Prof Kim Meador, MD.
- 29 March 2013, Recent imaging findings in juvenile myoclonic epilepsy and multimodal imaging in cryptogenic focal epilepsy, Christian Vollmar, MD.
- 26 April 2013, Neuroimaging and connectivity of the epileptogenic network, Prof Fabrice Bartolomei, MD, Maxime Guye, MD. Meetings will be held in the Kalyon Hotel Sultanahmet Istanbul at 6:30 p.m.

Officer Election Date

2014

Report By

Kadriye Agan

EPILEPSY SOCIETY UGANDA (EPISOU)

Publications

- 1. Article "Nodding Syndrome In Northern Uganda A Growing Threat For The Region." Dr Angelina Kakooza. *Epilepsy News Africa* (The newsletter of the Commission on African Affairs) Issue 2. Volume 1 Jan-Mar 2012. Page 10.
- Research article: "Clinical, Neurologic, and Electrophysiologic Features of Nodding Syndrome, Kitgum, Uganda: An Observational Case Series" James J Sejvar, Angelina Kakooza, Jennifer Foltz, et al. Lancet Neurology published online 8 January 2013 http://dx.doi.org/10.1016/S1474-4422(12)70321-6.

Meeting

We have held a series of local meetings since the inception of the Society in 2006.

Summary of Activities in 2011 and 2012

- Held a series of Mental Health Advocacy Forum meetings (2010-2011) with other partner NGOs to advocate for equal rights and opportunities for all people affected by mental, neurological and substance use problems in Uganda. We came up with a strategic document to guide the relevant stakeholders toward better essential services for people affected by mental, neurological and substance use problems.
- 2. Drs Richard Idro and Angelina Kakooza gave oral presentations at the 8th IBRO World Congress of Neuroscience in Florence, Italy 14-18 July 2011 on "Brain injury in cerebral malaria: Integrating clinical, biochemical, and brain imaging studies to assess pathogenesis" and "Prevalence and Clinical Description of Epilepsy in a Rural Community in Uganda," respectively.
- 3. Epidemiological multi-site survey of "Studies of the epidemiology of epilepsy in demographic surveillance sites" completed in the Iganga/Mayuge demographic surveillance site.

Summary of Activities in Relation to Global Campaign in 2011 and 2012

As a Society we are committed to dispelling the myths and raising awareness about epilepsy care and treatment in our country through audio visual media,

continuing medical education sessions, print medialocal newspaper articles and regular bulletins (media clips & newspaper articles have been produced during this period).

Educational Activities

- Held a successful three-day educational program in conjunction with the International Child Neurology Association (ICNA)/ Africa Child Neurology Association (ACNA) on the clinical aspects of childhood epilepsy in Africa, 2-4 February 2012 at the Lake Victoria Hotel, Entebbe, Uganda. (Delegates from 19 countries from Africa attended.)
- Wrote an article to educate the general public in The Uganda Health Information Digest, Volume 16, Number 1 January-April 2012 entitled "Seizure Disorders in Childhood."

Activities in Conjunction with Local IBE Affiliate

Partnered with Epilepsy Support Association Uganda (ESAU) to present the Epilepsy National Advocacy Conference on 7 December 2012. The Conference was aimed at creating a national forum of professionals, policy makers and other service providers to share experiences related to their work and explore avenues for future collaboration and networking in the field of epilepsy.

Future Plans

- To create awareness about epilepsy and encourage the public to be supportive to people with epilepsy. This will be in partnership with ESAU. We plan to target 10 primary schools within Kampala, have talks with the teachers and pupils on epilepsy, types, causes, prevention, management and referrals.
- 2. To develop information, education and communication materials on epilepsy. We plan to print posters and stickers on key messages about epilepsy. Sources of funding are being explored.
- 3. To formally set up an "Epilepsy Purple Day" in Uganda as an annual event to awareness about epilepsy countrywide.

Officer Election Date

February 2014

Report By

Angelina Kakooza

UKRANIAN LEAGUE AGAINST EPILEPSY (ULAE)

Summary of Activities in 2011 and 2012

- Annual Ukrainian League Against Epilepsy meeting, Kiev 12-14 May 2011
- Annual Ukrainian League Against Epilepsy meeting, Uzhgorod 11-13 October 2012
- Creation of Epilepsy Register 2012-2013, Creation of Experts Council 2012.

Educational Activities

- Free access to HINARI content provided by Ukrainian League Against Epilepsy for 2012-2013
- Visiting lecturers to different parts of Ukraine (every two months)
- Publishing Herald of Epileptology (journal of ULAE)

Future Plans

Visit of CEA Chairman to Ukraine for future actions coordination.

Officer Election Date

14 May 2011

Report By

Volodymyr Kharytonov

EMIRATES LEAGUE AGAINST EPILEPSY (UAE)

Summary of Activities in 2012

The year 2012 was a year of hard work in several fronts aiming towards helping people who have epilepsy, and in generating resources to further the mission through organized activities and volunteering. It was a year of remarkable developments and achievements.

- The First UAE Epilepsy Congress was held in Dubai from 13-14 April 2012. A total of 112 delegates attended the Congress and several interesting papers and up to date advances in the field of epileptology were presented.
- 2. Membership has increased, with an additional 12 members joining the Chapter since 1 January 2012. Namely, there is a constant increase in pediatricians, and neurologists.
- Three scientific meetings were held this year. They
 were attended by more than 30 delegates. These
 meetings were very well received and had
 generated fruitful discussions.

- 4. Epilepsy public awareness day took place on the same day of the opening of Emirates League Against Epilepsy (ELAE) 2012 Congress. It was attended by patients and families with epilepsy. The ELAE made educational materials available to the public and many brochures about the disorder were distributed in both Arabic and English languages. Furthermore, several radio talk shows and TV interview were held in that week to further enhance the mission of increasing the awareness and understanding of this disorder.
- 5. The ELAE has started a program to educate the healthcare providers about this disorder, diagnostic challenges and update them on various treatment modalities. The first program was held in Ras Al Khaima and was very well attended by more than 60 healthcare providers. The feedback of this activity was extremely positive.

Future Plans

- The preparation for the second UAE Epilepsy Congress is underway with an ambitious plan to host more delegates this year, both locally and regionally. Renowned international and regional speakers are invited to speak at the congress.
- 2. A Task Force for Epilepsy Purple Day 2013 is planning week-long activities aiming to increase public awareness about the disease through media forums, and other interactive open public sessions.
- 3. Reach-out programs will continue with a plan to reach out to other emirates thoughout the year.
- 4. Scientific Chapter meetings will use other formats in addition to didactic lectures and prepare challenging case studies, journal club materials, and EEGs cases.
- 5. We aim to work on enhancing the epilepsy support group activities in collaboration with our colleagues in the contributing hospitals.
- 6. Establish an associate category under which EEG technicians can subscribe, and to promote educational activities for them.

Prepared by

Taoufik Alsaadi, President, ELAE

UNITED STATES: AMERICAN EPILEPSY SOCIETY (AES)

Publications

Epilepsy Currents, AES News

Meetings

Annual Meeting and Biennial North American Regional Epilepsy Congress

Summary of Activities in 2011 and 2012

- The American Epilepsy Society held Annual Meetings in December (Baltimore, MD in 2011 and San Diego, CA in 2012). The 2012 meeting was the 4th Biennial North American Regional Epilepsy Congress. Both meetings were very well attended and provided many thought-provoking sessions. All of the presentations from the AES Annual Meetings are available on the AES website. (http://www.aesnet.org/go/professionaldevelopment/educational-opportunities/archivedaes-symposia)
- The Society celebrated its 75th Anniversary in 2011 with a special event at the 65th Annual Meeting in Baltimore, MD in December of 2011
- An ILAE Symposium, organized in cooperation with the North American Commission has been added to the Annual Meeting schedule and will be held each year
- Participated in the development of the Institute of Medicine's report: Epilepsy Across the Spectrum: Promoting Health and Understanding. Coordinating efforts of the Vision 20-20 group to accomplish the recommendations
- The Society maintains its accreditation from the ACCME to provide CME and also provides CE for nurses and pharmacists at its Annual Meeting
- The web-based member database and a membersonly professional networking site help make finding information and exchanging ideas easier for members
- AES cosponsored the Partners Against Mortality in Epilepsy conference in Chicago, IL in June of 2012
- AES cosponsored the Translational Workshop at the European Commission Congress in London, UK in September of 2012.

Research Funding

The Society raises money to fund research through its Annual Meeting, fundraising campaigns and through partnerships with other funding organizations. In addition it recognizes researchers worldwide for their work in all aspects of epilepsy. Recently, the Society presented awards to Simon Shorvon, MA, MD, FRCP (UK), Martin J Brodie, MD (UK) for lifetime contributions and accomplishments in the field of epilepsy, Richard Miles, PhD (France) for Basic Science and Renzo Guerrini, MD, (Italy) for Clinical Science.

The Society funded in 2011 (10/11)

- AES-funded Postdoctoral Research Training Fellowships (3)
- Postdoctoral Research Training Fellowship funded by the Lennox Trust Fund (1)
- AES and Lennox Trust Fund Pre-doctoral Fellowships (4)
- Research Initiative Program (1)
- Research Infrastructure Program (2)
- AES-sponsored Workshops (4)
- Research Recognition Awards (2)
- Targeted Pediatric Partnership (1)
- Clinical Research Training Fellowship/Susan Spencer Fellowship (1)

The Society funded in 2012 (11/12)

- AES-funded Postdoctoral Research Training Fellowships (3)
- AES and Lennox Trust Fund Predoctoral Fellowships
 (4)
- Research Initiative Program (1)
- Research Infrastructure Program (2)
- AES-sponsored Workshops (3)
- Research Recognition Awards (2)
- Targeted Pediatric Partnership (1)
- AES and Grass Foundation Young Investigators Travel Awards (8)

Educational Activities

- The educational pinnacle of the year is the Society's Annual Meeting, held in December, which provides a myriad of educational opportunities for clinicians, researchers and other epilepsy professionals. In addition, the Society repurposes all of the sessions from Annual Meetings and puts them on the website (www.aesnet.org) free of charge. The Meeting features one symposium presented in Spanish.
- In addition to many archived programs, the Society also offers web training sessions free of charge. There are two interactive web programs currently available. (http://www.aesnet.org/go/professional-development/education)
- Most of the materials in the online Epilepsy Education program have been translated into Spanish. This is a resource for teachers and students consisting of PowerPoint slides and text explaining basic aspects of epilepsy. The materials are available to everyone on the AES website (http://www.aesnet.org/professionaldevelopment/educational-opportunities/epilepsyeducation-program/epilepsy-education-program).

Activities in Conjunction with Local IBE Affiliate

- The AES leadership and staff participated annually, the Epilepsy Foundation's National Walk For Epilepsy, raising money for research
- Several members also participated in the Epilepsy Foundation's Public Policy Institute, learning about advocating to Congress and participated in visits to congressional people. The Society is participating in the web-based advocacy efforts of the Epilepsy Foundation
- Many members are active in national and state Professional Advisory Boards of the Epilepsy Foundation
- Several research funding vehicles are partnerships with the Epilepsy Foundation.

Future Plans

- Launching a Learning Management System on our website as a service to members and to help with Maintenance of Certification and Board Recertification requirements
- Launching EMUCaring, an online education program on safety in the epilepsy monitoring unit
- Taking over the Fellows programs that had been run in conjunction to our Annual Meeting which means bringing at least 50 young investigators to the meeting each year.

Officer Election Date

December 2012

Report By

M Suzanne C Berry, MBA, CAE

LIGA URUGUAYA CONTRA LA EPILEPSIA (LUCE)

Publications

Revista Uruguaya de Epilepsia 2011;20(1)(2) – 2012;21(1)(2)

Meetina

The 2012 Annual Meeting was held in Montevideo on 22 June with Prof Andre Palmini as invited speaker and Dr Pablo Pereda and Rodolfo Ferrando from the local staff of the Epilepsy Surgery Program.

Summary of Activities in 2011 and 2012

Development of an institutional blog, to enhance communication with the general public: http://ligaepi.blogspot.com. It allows download of

educational material for professionals and general public, as well as interaction and directly contacting LUCE's Directive Commission. In addition to our local agenda, members of LUCE participated actively in different ILAE Commissions and activities. Elections were held on 8 September 2012 according to LUCE's Constitution and Bylaws. The new authorities started 25 September 2012.

Summary of Activities in Relation to Global Campaign in 2011 and 2012

Under the request of the National Unit of Transit Security (UNASEV) we developed updated recommendations for acceptance and renewal of driving licenses in PWE. The LUCE participated in the Stand Up for Epilepsy campaign, with the collaboration of sportmen as Diego Forlán, Diego Lugano and Horacio "Tato" López. Members of LUCE were in the media (written journals, TV, radio), fighting against discrimination through education of the general public. Some patients did, as well, particularly in the context of our Annual Meeting and Anniversary of our Epilepsy Surgery Program. Then, we worked together with a group of patients to develop a session with their active participation, including presentation of the results of their survey on prejudice, discrimination and epilepsy in different areas of our country.

Educational Activities

Besides our Annual Meeting, devoted to epileptologists, neurologists and Neurology residents, LUCE supported the Epilepsy Section of the Neurological Institute providing every resident and postgraduate student with a free copy of some books on epilepsy provided by ALADE members (Elza Márcia Yacubian and Silvia Kochen). Members of LUCE participated in the Course of Epilepsy for Primary Care physicians, organized by the Latin American Commission of ILAE, and held in La Paz, Bolivia, as a parallel activity to the PanAmerican Neurology Congress of the WFN.

Activities in Conjunction with Local IBE Affiliate

Together with AUCLE (IBE affiliate) we could re-launch the Self-Aid Groups, under coordination of psychologists (Lic. Mariela Morales and Ana Bogacz), who are honorary collaborators of both institutions. The Group for patients started in July 2011, while the Group of relatives began on August 2012.

Future Plans

To improve design and content of our blog, including upload of our local journal, Revista Uruguaya de Epilepsia. To initiate a program of migratory courses on epilepsy diagnosis and management devoted to primary care physicians, in different areas of the country. First course planned to be in Melo city, April

2012. To perform an epidemiological project on posttraumatic epilepsy related to car accidents, with particular accent on its causes and preventive measures.

Officer Election Date

8 September 2012

Report By

Patricia Braga

YUGOSLAV UNION OF LEAGUES AGAINST EPILEPSY (SERBIA AND MONTENEGRO)

Publications

Series of Proceedings:

- Symptomatic epilepsies through the ages (13th Epilepsy School, 2011)
- Quality of life in epilepsy (14th Epilepsy School, 2012)
- 2nd EEG Workshop Manual (Kragujevac, 2009) Proceedings: New therapeutic approaches in TSC, Belgrade, 2012

Meeting

- 8th Congress of Serbian Neurologists (Kopaonik, 29 September – 2 October 2011)
- Symposium: New therapeutic approaches in Tuberous Sclerosis Complex, Belgrade, 7 July 2012.

Summary of Activities in 2011 and 2012

- 8th Congress of Serbian Neurologists with international participation (Kopaonik, 29 September - 2 October 2011) including teaching course on epilepsies
- Educational cycle of Epilepsy School courses
- Educational EEG Workshops
- Participation to the Project of EURAP. Collaboration with a number of other national ILAE Chapters, especially with regional Leagues
- Symposium on New therapeutic approaches in TSC, Bedlgrade, 7 July 2012.

Summary of Activities in Relation to Global Campaign in 2011 and 2012

 Educational and public-awareness activities developed in press and visual media. Lectures on a) Epilepsy and sporting activities b) Stigmatization of school children and adolescents c) difficulties in professional occupation and driving license procedure

 The 14th Epilepsy School was organized in Sumarice, Kragujevac 9-11 November 2012 and was completely dedicated to the Quality of Life in Epilepsy.

Educational Activities

- 13th Epilepsy School has taken place in Studenica Monastery, Serbia, 10-12 November 2011
- 8th Congress of Serbian Neurologists (Kopaonik, 29 September - 2 October 2011) - Teaching course: Differential Diagnosis of Epilepsies CME
- New therapeutic approaches in TSC, Belgrade, 7 July 2012
- 14th Epilepsy School, was organized in Sumarice, Kragujevac 9-11 November 2012
- 2nd EEG Workshop took place in Sumarice, Kragujevac, on 8 November 2012.

Activities in Conjunction with Local IBE Affiliate

No activities of local IBE have been recognized for years. No activities in conjunction with local IBE

Future Plans

- 1. 15th Epilepsy School, Monastery Dobrun, Republic of Srpska, September, 2013.
- 2. 3rd EEG Workshop, Monastery Dobrun, Republic of Srpska, September, 2013.
- 3. 16th Epilepsy School, Morovic, Serbia, November, 2014.
- 4. 4th EEG Workshop, Morovic, Serbia, November, 2014.
- Summer camp for leisure, sporting activities and friendship of children and adolescents, lasting 10 days (Kopaonik, Serbia) July 2013/2014.
- 6. Edition of the publications relating epilepsies, edited by League.
- 7. 9th Serbian Neurology Congress, Belgrade, November 2013.
- 4th Epilepsy Congress of Serbia and Montenegro 2014.
- Regional Epilepsy Conference, Kopaonik, Serbia, June 2014.

Report By

Prof Dr Nebojsa J Jovic, Chapter President



AWARDS

Morris-Coole Prize



Dr Schuchmann

Epilepsia is pleased to announce the winner of the 2011 Morris-Coole Epilepsia Prize – Sebastian Schuchmann – for the article "Respiratory alkalosis in children with febrile seizures" (Schuchmann S, Hauck S, Henning S, Grüters-Kieslich A, Vanhatalo S, Schmitz D, Kaila K. *Epilepsia* 52:1949–1955, 2011). The study was carried out in collaboration with a research group at the University of Helsinki, Finland.

Dr Schuchmann was be awarded the Prize and presented his lecture at the European Epilepsy Congress in London, on 2 October 2012.

COMMISSION ON EUROPEAN AFFAIRS

Presented at the 10th European Congress on Epilepsy in London, UK

Recognized for 100 years of service: ILAE Chapter of Great Britain



Simon Shorvon accepting award

Recognized for **75 years of service**: Dutch League Against Epilepsy



Gerrit-Jan del Haan, President, accepting award

Recognized for **50 years of service**:



Israeli Chapter



Italian League



Swiss League Against Epilepsy



French League

COMMISSION ON LATIN AMERICAN AFFAIRS

Presented at the 7th Latin American Congress on Epilepsy in Quito, Ecuador

Recognized for **50 years of service**: Argentinean League Against Epilepsy Brazilian League Against Epilepsy Chilean League Against Epilepsy Cuban League Against Epilepsy Peruvian League Against Epilepsy Uruguayan League Against Epilepsy

COMMISSION ON ASIAN AND OCEANIAN AFFAIRS (this award has not been presented yet)

Recognized for **50 years of service**: Japan Epilepsy Society

Asian and Oceanian Regional Congress Awards 2012

The following awards were presented at the 9th Asian and Oceanian Epilepsy Congress (AOEC) in Manila, Philippines in March 2012.

The Asian and Oceanian Outstanding Achievement Epilepsy Award (AOEA)

The Asian and Oceanian Outstanding Achievement Epilepsy Award (AOEA) was introduced by the Commission of Asian and Oceanian Affairs (CAOA) of the ILAE in 2010. The purpose of the Award is to recognize and pay tribute to medical or non-medical professionals for their extraordinary contributions to Epilepsy Care. It is our highest honor, and is given for the lifetime of the recipient.



The following people are shown above receiving the 2012 AOEA Award: Liwen Wu (China)
Pongsakdi Visudhiphan (Thailand)
Kurupath Radhakrishnan (India)
Sunao Kaneko (Japan)
Yushi Inoue (Japan)
Leonor Cabral-Lim (Philippines)

Also shown: Byung In Lee (Korea) Josephine Gutiérrez (Phillipines) Robert Cole (Australia)

Outstanding Person with Epilepsy Award 2012

The Outstanding Person with Epilepsy Award was created to encourage people with epilepsy to not be ashamed of their condition and to overcome the heavy culturally defined stigma and discrimination that exist in the Region. This Award is presented to very worthy recipients, nominated by their respective Chapters, at the subsequent Congresses.



The following people were honored with the Outstanding Person with Epilepsy Award: Yung-Chich Chen (Taiwan)
Fai Ming Hung (Hong Kong)
Baldwin Chua Kho (Philippines)
Martin Raffaele (Australia)

The following honorees are not shown: Purevjav Tsoatsaikhan (Mongolia) and Yashoda Wakankar (India)

Tadokoro Award

In order to encourage young researchers in epileptology in the Region, best presentation prizes are awarded for both Platform and Poster presentations. The award is in honor of Dr Tadokoro, a retired epileptologist from Japan who contributed generously to the activities of the ILAE Commission on Asian and Oceanian Affairs (CAOA).

Best Oral presentation: 1st Prize — Yu-Wen Hung (China) 2nd Prize — Dae Lim Koo (South Korea)

Best Poster presentation:

1st Prize: Sarah Heron (Australia) 2nd Prize: Sandeep Kaushel (India)

EUROPEAN REGIONAL CONGRESS AWARDS

The following awards were presented at the 10th European Congress on Epilepsy in London, October 2012.

European Epileptology Award 2012



Christian Elger

The European Epileptology Award is awarded every two years by the ILAE Commission on European Affairs (CEA) to a European epileptologist in recognition of his or her outstanding contribution to European epileptology.

Young Investigator Regional Award



Pasquale Striano

Presented in recognition of outstanding contributions to epilepsy research. The award is given to stimulate a promising research career in epileptology. It consists of a diploma and carries no monetary value but the recipient's European Congress registration fee is waived. The Awards are made no more than once every two years and to a maximum of two awardees, one in basic science and one in clinical science, on every occasion.

European Epilepsy Education Award



Alla Guekht

The award is given in recognition of outstanding contributions to European epilepsy education. The award consists of a diploma and carries no monetary value. It is announced in conjunction with the European Congress on Epileptology to which the awardee will have the registration fee waived. Awards are made no more than once every two years and to a maximum of one awardee on every occasion

European Epilepsy Service Award



Ann Little

The award is given in recognition of outstanding service contributions to European epileptology. The award consists of a diploma and carries no monetary value. It is announced in conjunction with the European Congress on Epileptology to which the awardee will have the registration fee waived. Awards are made no more than once every two years and to a maximum of one awardee on every occasion.

Individuals in Europe of any profession that have made outstanding service contributions to European Epileptology and that have not received the Ambassador of Epilepsy Award are eligible for the European Epilepsy Service Award

ILAE British Branch Excellence in Epilepsy Award

The ILAE-British Branch presented the Excellence in Epileptology award to Chrysostomos (Tomis) P. Panayiotopoulos, for his outstanding work in epilepsy semiology, classification and electrophysiology.

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.
- 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:

- 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.
- 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

- 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.
- 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.
- 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.
- 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

- 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.
- 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

- 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.
- No expenses shall be incurred by a Commission or Task Force on behalf of the ILAE without the consent of the Executive Committee.
- 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

- 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

- 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.
- 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

- 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;
 - 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 Email broadcasts, the ILAE website, *Epigraph* and other publications;
- h) Serve as an ILAE representative on the IBE Executive Committee and maintain liaisons with other related organizations;
- Monitor the activities, programs, and developments of ILAE, supporting and promoting policies and programs adopted by the Chapters, Executive Committee, and Commissions;
- i) Provide the leadership for monitoring the ILAE Strategic Plan;
- Recommend initiatives, research, and special assistance whenever necessary for Executive Committee approval;
- I) 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.
- 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;
 - 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;
 - Represent ILAE with other associations or entities as assigned by the President or Executive Committee;
 - 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;
 - 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;
 - Retain authority and responsibility for the financial activity of ILAE when such activities are delegated to staff or contracted with an external entity;
 - 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;
 - 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.
- The Management Committee will meet as needed between meetings of the entire Executive Committee.
- 7. 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 regarding number and role of Associate Editors and Managing Editor;
- Appoint the Associate Editors and the members of the Editorial Board, and supervise communication with the Board;
- 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.
- 8. The President, Secretary-General and Treasurer of IBE serve as Ex-Officio, non-voting members of the ILAE Executive Committee. Their function is to facilitate a close and collaborative understanding between IBE and ILAE.

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 arbitrate on matters referred to it by the Editor(s)-in-Chief, but shall leave the day to day conduct of the Journal entirely to the Editor-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.
- 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 out-going 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

- 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.
- 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

- 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.
- 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.
- 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)

- 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, constitutionallydefined 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.
- 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.
- A quorum for a JEC shall be the presence of a majority of the members of each of the ILAE and IBE Executive Committees.
- 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.

Approved October 2011