Commission Chair Report – Overview of Accomplishments  
Saturday, June 22, 2013 – Montreal, Quebec

Commission Reports

Commission on African Affairs - Amadou Gallo Diop

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<thead>
<tr>
<th>TASK</th>
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<tr>
<td>Training</td>
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<tr>
<td>• Identify centers with training capacity.</td>
<td>• Done</td>
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<td>• Identify teaching resources</td>
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<tr>
<td>• Hold educational meetings</td>
<td>• Nairobi 2012 and Dakar 2013</td>
<td>• Nairobi during 1st AEC and French session next month in Dakar to replace Bamako (political instability)</td>
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<td>• Visiting professor initiative</td>
<td>• France (Genten, Farnarier  Canada (Carmant et coll.) next July 2013</td>
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Communication and Advocacy

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<th>TASK</th>
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<tr>
<td>• Quarterly news report</td>
<td>• Done</td>
<td>• Fourth newsletter will be available during IEC Montreal.</td>
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<tr>
<td>• Update GCAE document in French, English, Portuguese</td>
<td>• Not yet done, to be discussed with WHO, IBE and ILAE</td>
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Research

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<th>TASK</th>
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<tr>
<td>• Generate publications</td>
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<td>• Focused research</td>
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<td>• Monitored progress</td>
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<tr>
<td>• Neurology directory</td>
<td>• Done</td>
<td>• Shared with PAANS, WFN and SONA</td>
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<td>• Research database</td>
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Commission of Asian & Oceanian Affairs - Byung In Lee

Action Plans of CAOA during the term from 2009-2013
1. Construct CAOA Website linked with ILAE-Website and individual CAOA-Chapter Websites and publish CAOA-Newsletter (by Information committee): Achieved as planned
   (1) CAOA website (http://www.caoa-epilepsy.org)
   (2) Published the first CAOA-Newsletter on December. 2012

3
2. Enhance educational and training efforts and activities (by ASEPA): **Achieved as planned**
   (1) Teaching courses and workshops in regions in need (provides 10 to 12 courses per year)
2) Epilepsy Fellowship for future epilepsy Specialists in the region (provides 2 ASEPA Fellowships/year and another 2-4 Fellowships/year in collaborations with Epilepsy Research Foundation of Japan, Japan Epilepsy Societies, and Epilepsy Society of Australia)
   (3) Promote skills in EEG recording and interpretation (ASEPA EEG-Certification examinations and EEG teaching courses in collaboration with ANZAN)
   (4) Publish Proceedings of AOEC in Neurology-Asia
3. Organize the Asian and Oceania Epilepsy Congresses every 2 years: **Achieved as Planned**
   (1) 8th AOEC in Melbourne in October, 2010
   (2) 9th AOEC in Philippines in March, 2012
4. Stimulate Clinical and Translational Research (by Research TF): **Achieved as Planned**
   (1) Stand-alone meeting of Research TF in Taipei on July, 2011
   (2) under preparation of the CAOA-Research Priority document
5. Promote New Chapter Formation: **Achieved as Planned**
   (1) Vietnam in 2009, (2) Sri Lanka in 2011
6. Facilitate Global Campaign Against Epilepsy Activities (by GCAE TF): **Achieved as Planned**
   (1) GCAE workshops at the 8th and the 9th AOEC
   (2) Stakeholders meeting at the 9th AOEC
   (3) Planning a CAOA-demonstration project for the reduction of Treatment Gap in Asia
7. Facilitate interactions among chapters and commissions: **Achieved as Planned**
   (1) Joint symposium with Asian Epilepsy Surgery Congress in Hong Kong, 10th Nov, 2011
   (2) Joint symposium with Infantile Spasm Society in Tokyo, Japan, on Feb, 2012
   (3) Active participation of ASEPA and CAOA with Congresses, Summer Schools, or Epilepsy Symposia held by individual chapter
   (4) Planning a Joint symposium with AOCN in Hong Kong, 2014
8. Initiate the Asian and Oceania Outstanding Achievement Epilepsy Award (AOEA): **Achieved as Planned**
   (1) First AOEA at the 8th AOEC at Melbourne (2010), 5 award recipients: H. Aziz (Pakistan), T. Tanaka (Japan), K. Yagi (Japan), P. Satishchandra (India), X. Wu (China)
   (2) 2nd AOEA at the 9th AOEC at Manila, Philippines (2012), 6 Award recipients: L. Cabral-Lim (Philippines), Y Inoue (Japan), S Kaneko (Japan), K Radhakrishnan (India), L Wu (China)

Commission on Eastern Mediterranean Affairs - Ahmad Beydoun - report not available

Commission of European Affairs – Meir Bialer

CEA Key Accomplishments 2009-2013
a. Established the CEA Strategic & Action Plans in accordance to the ILAE strategic plan
b. Established the European Education Agenda
c. Established the migrating, EPODES & the Elat Educational courses as CEA Core Courses (CCC)
c. Supported the annual San Servolo, Stereo-EEG, VIREPA, Baltic and Caucasian Summer Schools, as CEA-Sponsored Activities (CSA)
d. Continuing the European Congresses on Epileptology (ECE) as one of the most successful international scientific epilepsy congresses
e. updated the ECE guidelines
f. Promoted Epilepsy Advocacy & Research in Europe (EAE) through a joint ILAE-IBE Task Force (JTF), in partnership with European ILAE chapters and IBE associations
g. Inclusion of epilepsy research on the 2012- EU-FP-7 call for grant proposals
h. Established collaboration between the CEA & the ILAE-North American. A joint CEA-CNA symposium at the 2011 & 2013 AES & 2012-ECE
i. Started a collaboration with the ILAE-CAA (Commission on African Affairs) aiming to answer unmet educational needs in Africa
The major achievements fulfilled 6 key aims.

**Aim 1-Articulate internationally applicable guidelines for diagnosis & treatment of patients with epilepsy in Europe**

**Action:**
We appointed a panel of CEA liaisons in order to disseminate guidelines to the wider neurological community in Europe:

Arzimanoglou: Communication
A. Covanis: Global Campaign
H. Cross: Education & EPNS
A. Guekht: EFNS
Pitkanen: Basic science

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

**Action:**
a) Established an educational agenda which has been made available to all on the CEA website with procedures for applications for CEA supported course/symposia and have promoted this to the European Chapters.
b) Two types of educational courses:
   i) CEA-Core Courses (CCC): 1) Clinical Epileptology (Migrating Course -MC); 2) Pharmacology (Eilat Edu); 3) EPODES (Surgery)
   ii) CEA-sponsored activities (CSA): e.g. Basic & translational Science, Pediatrics (San Servolo); 2) Stereo EEG (Lyon); 3) Regional Courses: Caucasian & Baltic-Sea Summer Schools on Epileptology
c) In addition we have welcomed and promoted ideas for new regional courses.

**Aim 3 - Stimulate & enhance basic & clinical research in epilepsy in Europe**

**Action:**
a )Extensive activity via the Epilepsy Advocacy Europe (EAE) with EU executives (directly & via various ILAE-Chapters) succeeded in giving epilepsy research priority in EU funding with a major European call for 2012- FP7 grants related to translational epilepsy research.
b) CEA-EU Symposium (Rhodes & London-ECEs), Dublin EREF2013 & 2014-Stockholm-ECE.
c) Support scientific conferences with European added value that publish post-conference proceedings (e.g. status epilepticus, inflammation).

**Aim 4- Work with other European Organizations to catalogue current epilepsy care in Europe & determine its needs**

**Action:**
we have liaised with major European neurological societies including:
a) ILAE-CEA & EFNS joint symposia since 2011
b) ILAE-CEA & ESRS joint symposia :2012-ESRS & 2014-Stockholm-ECE (ESRS - European Sleep Research Society

**Aim 5- Prompt & facilitate initiatives that improve standards of comprehensive care (diagnosis, treatment & 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, AES-2010, Rome-IEC) & a JTF-EMA-FDA meeting on regulatory issues (Paris -17/11/2011)
b) Forthcoming White Papers to the FDA: 1) using add-on therapy for a combined monotherapy/add-on therapy indication; 2) extrapolation of adult partial onset seizure data to children; 3) use of the time to event analysis for pivotal trials.

Aim 6- Ensure that ILAE’s organizational structure is efficiently & effectively dedicated to fulfilling ILA mission

Action:
a) Continuous update of European chapters’ chairs & secretaries (via Gus Egan)
b) Establish ILAE chapters in the 3 remaining European countries
c) Updated CEA rules in accordance with the ILAE-EC constitutional amendment
d) Updated ECE rules to be applied from 2016 on.

Commission on Latin American Affairs – Manuel Campos

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

The main fact for the regional development is “Education”:

1) LASSE (Latin American Summer School in Epilepsy): for more than seven years Dr. Esper Cavalheiro and the Brazilian colleagues organize with the support of the Brazilian Government and ILAE the main regional meeting for young people and best epilepsy professors in the world. From LASSE each year is coming new generations of epileptologists for the region. Now we can see many young epileptologist in his ILAE chapters.

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

3) LACE (Latin American Epilepsy congress): Each two years the epilepsy community has the opportunity to meet us. There we have also the opportunity of meeting all ILAE chapters. Quito 2012 (president: Dr. Patricio Abad) was our VII LACE with a great successful.

4) Epilepsy fellows in the region: Our commission has performed the identification of the best and certificated “Epilepsy Centers” in Latin America for epilepsy training (clinical, EEG, surgery, etc.). With the support of ILAE we have given more than 12 fellows in the last few years, each one coming of countries with low epilepsy development and after the fellow they have the compromise to work in his ILAE chapter and the public system.

5) Meeting of “Latin American Epilepsy Centers”: Its activity began 2010 as a small meeting organized in Uruguay (by Dr. Patricia Braga), but now with the ILAE support we had our IV meeting last May 2013 in Santiago, Chile. There we have more than 40 Epilepsy Centers of 14 different countries and 220 participants (120 aren’t Chilean). Sure this activity has a different orientation than LACE´s in order to create epilepsy consensus and more contact between the different epilepsy groups in the region.

6) New Chapters: with the special work of Dr. Eduardo Barragán, El Salvador and Bolivia are our new ILAE chapters; with these 2 countries we have the whole region with active chapters. But we have some chapters without democracy, where the same people remain for many years and stop the development of the new epilepsy generations. We, as Latin American commission,
don’t have the tools for a solution, because each country is independent, but our alternative way is to support the young people with epilepsy interests in these countries.

7) **Relationships with North America’s sub-commission:** The principal activity is our “Spanish Symposium” each year at the AES Congress, where we have in average 200 assistants. Inclusive the main sessions at the congress have simultaneous translation. We have the best educational relationship with our North American partners.

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

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

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

To finish I would like to thank to all my commission friends, but specially to Patricia Braga (treasure), Eduardo Barragán (secretary), Franz Chaves (Web-site), Esper (LASSE) and Elza Marcia Yacubian (ALADE) for the permanent work and support.

Manuel Campos, Chairman

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**Commission on North American Affairs – Sheryl Haut**

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

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

Systematic review: The Stigma task force has nearly completed reviewing 700 full text articles identified by review of 4123 abstracts related to stigma in epilepsy. Data abstraction began in April 2013 with results anticipated and manuscript preparation planned by spring/summer 2013.

Stigma Symposium: ILAE meeting, Montreal 2013. The symposium proposal submitted jointly by NAC and the Commission on Stigma was accepted for the upcoming Montreal meeting, chaired by Dr. Jette.

**Main Session: Stigma in epilepsy - who, why and what to do?**

- **Translation project - pilot Spanish translation of 2 symposia at AES, expansion to be explored**
Translation was provided for 2 symposia at AES 2012. The translation units were utilized by a very small number of attendees. The need and future of this program will be discussed with the Latin American Commission in Montreal.

- **Visiting professorships – good project for export to other regions**
  - Strengths: Has established enduring collaborations between centers; has effected local change
  - Challenges: Identifying needs and assessing outcomes; identifying appropriate sites; choosing partnerships with long term potential

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

This program was more recently extended to Africa, in collaboration with the African Commission. The education task force worked with Dr. Carmant and the African Commission to develop a call for proposals for visiting professorships to Africa, and supported these fellowships. The task force and others reviewed the proposals and selected the top 3 for funding. These visits took place and 3 more are planned for 2013.

- **Telemedicine**

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

- **International symposia/courses**

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

- **Regulatory affairs**

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

A white paper is in process to propose the elimination of separate indications for monotherapy and add-on therapy. Similarly, a white paper is being considered to present the pediatric approval proposal to the FDA following a (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 2013 will help to direct these efforts.

- **Neuro-cysticercosis prevalence project – manuscript in late 2012**

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

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

- **IOM report – dissemination of recommendations**
The NAC, with the ILAE, participated in the release of the IOM report on epilepsy, and has continued to work with IOM Healthcare providers group on the implementation of the IOM recommendations. Most recently, the NAC provided an inventory of activities related to specific IOM recommendations. NAC members have also been active participants in the epilepsy screening tool initiative, one of the first deliverables of the IOM.

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

The PAHO task force of the NAC has been working closely with the PAHO task force of the Latin American Commission, as well as other members representing the ILAE including Drs. Mather, Beghi and Hesdorffer. Following an initial meeting in 2011, a large meeting took place at the Latin American Congress in November 2012, where the NAC will worked concert with the Latin American Commission, the European Commission, the Epidemiology Commission and the Global Outreach Commissions to help formulate a roadmap for the implementation of PAHO over the coming years. The NAC representatives provided insights into many projects consistent with the PAHO mandate that have been successfully completed during the past 2 terms. Additionally, the IOM report provided potential examples of regulatory progress in epilepsy care and this will be discussed. As the PAHO epilepsy initiative is in its early stages, it is anticipated that the NAC will continue to be closely involved in PAHO in the coming term, including participation in the PAHO meeting scheduled in Santiago 2013.

- **Formation of the Epilepsy Society of the Caribbean**

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

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

- **Travel support**

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

- **Website development**

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

**Challenge**

- **Incorporating the work of topic-oriented commissions**

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

- **Disparities study needs to be done**

To be discussed with the new Commission.

**Charge**

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

See above

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

**Classification Commission – Ingrid Scheffer**

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

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

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

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

Diagnostic Methods Commission – Fernando Cendes

The work of the diagnostic methods commission involved several task forces during the period of 2009-2013. For the list of members please see http://community.ilae-epilepsy.org/diagnosticmethods/MEMBERS.

The focus of the neuropathology sub-commission was on a new proposal for the classification of focal cortical dysplasias (FCDs) and Hippocampal Sclerosis (HS). The task force on FCD published the “The clinicopathologic spectrum of focal cortical dysplasias: a consensus classification proposed by an ad hoc Task Force of the ILAE Diagnostic Methods Commission” (Blümcke et al, Epilepsia 2011;52:158-74); and the task force on HS just finished a Consensus Classification of HS that was published recently in International consensus classification of hippocampal sclerosis in temporal lobe epilepsy: Blümcke et al. A Task Force report from the ILAE Commission on Diagnostic Methods. Epilepsia 2013 doi: 10.1111/epi.12220.

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

The three main goals of the neuroimaging sub-commission and task force were to (1) formulate “evidence-based” guidelines on “role of imaging in Paediatric Surgery”, (2) evaluate the “role of advanced imaging methods in Epilepsy Surgery” and (3) promote global education/training in neuroimaging for neurologists and radiologists. Guidelines for imaging infants and children with recent-onset epilepsy were published in Epilepsia in 2009 (50:2147-53), and a commentary on diagnostic testing study guidelines and practice parameters in Epilepsia (2011 52:1750-6). During meetings in Boston (AES 2009) and Rome (ILAE 2011), they prepared for a 3-day workshop in London from 27-29th September 2012, which
comprehensively assessed the clinical role and use of EEG-fMRI, cognitive fMRI for language and memory, as well as the added value of PET and SPECT, and post-processing of MRI. This workshop forms the basis of a “position paper” of expert opinions on the clinical use of these advanced imaging methods, soon to be submitted to the executive committee of the ILAE for publication in Epilepsia. A long distance neuroimaging teaching programme was formally accepted by the ILAE. Members of the imaging task force participated in the annual web Neuroimaging courses offered by Virepa, which included students from different parts of the world. Some of the students were supported by scholarships offered by ILAE.

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

Projects for next period (2013 – 2017)

The Task Forces of the ILAE Commission on Diagnostic Methods would like to continue their successful work and complete their specific aims and to continue to develop better tools and protocols for diagnostic methods in epilepsy care. Commission members would also like to develop mechanisms to assess cost-effectiveness and accuracy of pre-surgical evaluation protocols, including neuroimaging, neurophysiology and neuropsychology procedures.

We plan to continue to work on the development of optimal guidelines for patients with refractory epilepsies and "negative MRI".

In addition to the dissemination of the ILAE consensus classification systems for FCD and HS at national and international scientific meetings and the further promotion of collaboration with the ILAE Neuroimaging Task Force, a major task for the up-coming period is to improve the classification and the definition of diagnostic guidelines for tumors associate with the chronic epilepsies. These guidelines should then be referenced in the up-coming revision of the WHO classification system for Brain Tumors to achieve world-wide recognition and dissemination.

Education Commission – CT Tan

Achievements and challenges of the Education Commission (2009-2013)

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

(1) The educational efforts by the regional commissions

The European, Asian & Oceanian and Latin American commissions continue to have robust educational activities. In particular, summer school is now a regular feature in China and India, as well as Europe and Latin America. Fellowship of 3-12 months duration is now a regular activity in Latin America as well as Asia Oceania. There is also a small fellowship program as joint venture with WFN, involving Mozambique. The ASEPA EEG certification examination is progressing well and making significant impact to EEG practice in some of the countries in Asia.
The North American Commission continues with its visiting professorship program to the Caribbean and Latin American countries, and has extended it to Africa. The African Commission was formed in 2011 and had their first successful Congress in 2012.

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

(2) Online Education and other projects

Distance learning courses (VIREPA)

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

e-Textbook

The basic idea is to provide authoritative information for professionals who look after epilepsy, which is under open access. It also allows for more members of the ILAE community to contribute towards ILAE activities (a conduit for the "Faculty of 1000" to contribute). This project is under SH Lim as the Editor. The project has been started but progress up to now has been slow. To-date, there are less than 20 chapters at various levels of editorial work.

This project potentially will have significant impact; there are also proposals to translate the textbook to Chinese and Spanish. It is a challenge for the next commission to consolidate and expand the project.

Recorded presentations

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

Epileptic Disorder

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

Epidemiology Commission – Dale Hesdorffer, Ettore Beghi

Task force on comorbidity
Chair Dale C Hesdorffer, Members: Christopher Helmsteader, Roberto Tuchman, Ettore Beghi, Andres Kanner

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

Two of the focuses were also part of the Commission on Psychobiology. They were proposing instruments to assess epilepsy comorbidities; and creating training materials for clinicians in order to identifying comorbidities and understand their impact on epilepsy prognosis and quality of life. As such they stayed in the Commission on Psychobiology and the more epidemiological aims retained in the task force.

Early on the task force decided to focus on the psychiatric and cognitive comorbidities as the full scope of the effort was too large for the number of task force members.

Questions to address in the systematic review were developed to be similar for the psychiatric and cognitive comorbidities, although some questions were added that were unique to one or the other. An aspect of all the questions was examining children separately from adults when possible, as well as separate examinations by epilepsy etiology, and seizure type. The questions were:

1. Were the comorbidities more common in epilepsy than in the general population? This question is to be answered, using cross-sectional studies in adults and children.
2. Is the comorbidity associated with an increased risk for developing epilepsy or a first unprovoked seizure? This question relies upon case-control studies of incident epilepsy and controls or prospective or retrospective cohort studies of a comorbidity where epilepsy is an outcome.
3. Is epilepsy or unprovoked seizure associated with an increased risk for developing a specific comorbidity?  This question relies upon prospective or retrospective cohort studies of epilepsy compared to controls where the comorbidity is the outcome or studies of prevalent epilepsy where incident comorbidity is the outcome.
4. Is the comorbidity when it occurs with epilepsy different from the comorbidity when it doesn't occur with epilepsy? This question relies upon case-control studies of incident epilepsy and controls or cross-sectional studies in the general population that include epilepsy or prospective or retrospective cohort studies of a comorbidity where epilepsy is an outcome.
5. Does the comorbidity occur during the pre-ictal and post-ictal period more than during other periods? This question relies upon Cross-sectional studies of epilepsy or prospective or retrospective cohort studies of epilepsy that specifically examine the pre-ictal and post-ictal period.

Following the creation of the questions, a set of key words were developed for the search for the psychiatric comorbidities and separately for the cognitive comorbidities.

For the search on cognitive comorbidities (itemized below) 1,587 articles restricted to humans were yielded after combining searches in medline and pubmed.

**COGNITIVE COMORBIDITY SEARCH**

**Epilepsy**
Epilepsy/ or exp epilepsies, myoclonic/ or exp epilepsies, partial/ or exp epilepsy, benign neonatal/ or exp epilepsy, generalized/ or exp epilepsies, post-traumatic/ or exp epilepsy, reflex/ or exp landau-kleffner syndrome/ or exp seizures/ or exp status epilepticus/

**Epidemiological studies**
epidemiologic studies/ or exp case-control studies/ or exp retrospective studies/ or exp longitudinal studies/ or exp cross-sectional studies/ or exp intervention studies/

**Cognitive Disorders**
behavior and behavior mechanisms/ or neurobehavioral manifestations/ or exp apraxias/ or memory disorders/ or exp amnesia/ or exp mental retardation/ or perceptual disorders/ or exp agnosia/ or auditory perceptual disorders/ or psychomotor disorders/ or exp apraxia, ideomotor/ or cognition/ or exp
awareness/ or exp cognitive reserve/ or exp comprehension/ or exp executive function/ or learning/ or exp "critical period (psychology)"/ or exp memory/ or exp problem solving/ or exp verbal learning/ or auditory perception/ or exp speech perception/ or "theory of mind"/ or exp thinking/ or concept formation/ or exp creativeness/

**Mental disorders in childhood**
mental disorders diagnosed in childhood/ or exp attention deficit disorder with hyperactivity/ or exp child development disorders, pervasive/ or exp learning disorders/ or exp developmental disabilities/ or exp mental retardation/ or exp motor skills disorders/ or exp schizophrenia, childhood/

**Language**
language disorders/ or exp aphasia/ or exp articulation disorders/

For the search on cognitive comorbidities (itemized below) 1,006 articles restricted to humans were yielded after combining searches in medline and pubmed.

**PSYCHIATRIC COMORBIDITY SEARCH**

**Epilepsy**
Epilepsy/ or exp epilepsies, myoclonic/ or exp epilepsies, partial/ or exp epilepsy, benign neonatal/ or exp epilepsy, generalized/ or exp epilepsy, post-traumatic/ or exp epilepsy, reflex/ or exp landau-kleffner syndrome/ or exp seizures/ or exp status epilepticus/

**Epidemiological studies**
epidemiologic studies/ or exp case-control studies/ or exp retrospective studies/ or exp longitudinal studies/ or exp cross-sectional studies/ or exp intervention studies/

**Psychiatric disorders**
mental disorders/ or exp agoraphobia/ or exp obsessive-compulsive disorder/ or exp panic disorder/ or exp phobic disorders/ or exp stress disorders, traumatic/ or exp dissociative disorders/ or exp anxiety, separation/ or exp "attention deficit and disruptive behavior disorders"/ or exp schizophrenia, childhood/ or exp mood disorders/ or exp neurotic disorders/ or exp personality disorders/ or exp "schizophrenia and disorders with psychotic features"/ or exp somatoform disorders/ or exp substance-related disorders/

These abstracts were reviewed by three sets of pairs in the task force and 270 articles were selected for the cognitive comorbitidies and 297 articles were selected for inclusion for the psychiatric comorbidities.

An abstraction form was created. This was then set up in google docs with a connecting excel file to receive the data. The link for the psychiatric comorbidity form is https://docs.google.com/spreadsheet/viewform?fromEmail=true&formkey=dHhTZkpWeklyWUo0XzJKSE M1NkZLbnc6MQ and the like for the cognitive comorbitidies is https://docs.google.com/spreadsheet/viewform?fromEmail=true&formkey=dJNWE5PcVhNTTBNcFNqTnF1YXN6N1E6MQ and the like for the cognitive comorbidity for is https://docs.google.com/spreadsheet/viewform?fromEmail=true&formkey=dJNWE5PcVhNTTBNcFNqTnF1YXN6N1E6MQ and the like for the cognitive comorbitidies is https://docs.google.com/spreadsheet/viewform?fromEmail=true&formkey=dJNWE5PcVhNTTBNcFNqTnF1YXN6N1E6MQ and the like for the cognitive comorbitidies is https://docs.google.com/spreadsheet/viewform?fromEmail=true&formkey=dJNWE5PcVhNTTBNcFNqTnF1YXN6N1E6MQ and the like for the cognitive comorbitidies is https://docs.google.com/spreadsheet/viewform?fromEmail=true&formkey=dJNWE5PcVhNTTBNcFNqTnF1YXN6N1E6MQ. Since every article had to be reviewed and tabulated by two individuals, we realized that more task force members were needed and request that the task force be continued with additional members in order to finish this important task to which much time has already been devoted.

**Report on the Mortality Task Force**
Submitted by David Thurman, Co-chair

Meeting in Rome, Italy in September 2011, in Baltimore, USA in December 2011, and in London, UK in October 2012, the Mortality Task Force has clarified its objectives, developed its methods, and pursued its work plan.

The objectives of the Mortality Task Force are to

1) Identify and quantify causes of death in people with epilepsy, including underlying causes / risk factors for epilepsy, and direct consequences of epilepsy or seizures; and to identify risk factors for preventable causes of death in epilepsy; and
2) Identify potential prevention strategies to reduce the burden of mortality in epilepsy.
Two subgroups of the Task Force are completing systematic, evidence-based literature reviews and analyses to accomplish these goals.

- The first subgroup, focused on mortality in higher-income countries and regions, has completed its initial search of indexed medical publication databases (Medline and Embase), identified relevant titles and abstracts, assessed the quality of evidence of these articles, extracted data, and entered these data in a computer database. We expect the analysis and synthesis of these various data and the preparation of a manuscript for publication that will accomplish Task Force Objective 1 anticipated for completion in the next 4 to 6 months.

- The second subgroup, focused on mortality in lower income regions, is similarly engaged, having completed its initial search for relevant publications and the screening of titles and abstracts, with the extraction of relevant data underway.

The Task Force will commence activities to accomplish Objective 2 after submission of the report for Objective 1.

**Report on the Reliability Task Force**

Submitted by Ettore Beghi, Chair

**Purpose:** To develop a software to test the reliability of established and new classifications of the epilepsies. The work was done with repeated interactions with the Commission on Classification.

**Members:** Ettore Beghi (Chair); Donna Bergen, Peter Bergin, Giuseppe Capovilla, Jacqueline French, Allen Hauser, Dale Hesdorffer, Marco Medina, Charles Newton, Douglas Nordli

**Timeline & Milestones**

1. **Rhodes, Greece, July 2 2010:** The objectives, methods, timeline, tasks and deliverables of this task force were outlined. The members of the TF were asked to participate in a validation study of different classifications of seizures and epilepsies. The validation process would incorporate the assessment of the validity and reliability of categories reflecting the different levels of diagnostic certainty provided in the position paper on the standards for epidemiologic studies and surveillance of epilepsy (Thurman et al, Epilepsia 2011; 52 (suppl.7): 2-26).

2. **Rome, Italy, August 28 2011:** The aims and structure of the study focusing on the reliability of four different classifications of the epilepsies (ICD-10, the forthcoming ICD-11 codes, etiology & seizures) were presented. The ICD-11 classification, commissioned by the WHO, was a modified version of the new ILAE Classification proposal (Berg et al, Epilepsia 2010; 51: 576-85). The members of the Reliability TF would be the raters for the different classifications. A number of case reports from different sources would be made available for testing. The information regarding each case report was to be presented in three subsequent steps to comply with the increasing information coming from the diagnostic process and to envisage different scenarios, ie, very limited information as provided by history and physical examination (step 1), additional data from EEG findings (step 2), and more complete diagnostic assessment through imaging and other diagnostic tests (step 3). Inter-rater agreement would be tested with the kappa statistic.

3. **Baltimore, US, December 3 2011:** The material to be used for the reliability testing (case reports, forms) was finalized. The case reports (N=71) would be accessed through a web site and web forms of the four classifications would be made available early in 2012. The TF members who declared their willingness to participate in the reliability test included EB, DB, GC, DN, PB, WAH, and Judith Bluvstein from JF’s group.

4. **London, UK, October 1 2012:** A report was made of the results of the reliability test, which had been summarized in a scientific manuscript and discussed with all the TF members. Regarding the ICD-10 and ICD-11 codes, the inter-rater agreement was mostly poor at step 1 and only slightly improved at steps 2 and 3 with no significant differences between the two classifications. The agreement was good to excellent for some seizure types only and varied significantly across etiological factors. Intra-rater agreement was excellent. The data raised a discussion on the limitations of the procedure adopted to test inter-rater reliability in using differing diagnostic codes and classifications in epilepsy.
A second reliability test was thus planned during the Latin American Epilepsy Congress in Quito, November 14-17 2012. Given the site and time constraints, the structure of the validation study was simplified and only the ICD-10 and ICD-11 codes would be tested. Involved would be a sample of adult and child neurologists from Latin American countries attending the meeting. These physicians would be invited to a full-day meeting to examine 25 case reports. Each case report would be presented in two steps only (steps 2 & 3 combined).

**Deliverables:**

1. Scientific report of the results of the first reliability test; the data presented in the first version of the manuscript, after the discussion in London and a subsequent recommendation of the ILAE President, were the object of a second, independent statistical analysis (to be performed by Emilia Bargella from DH's group), which led to the preparation of a revised version of the text, now ready for the final revision by the TF members. After revision, the text will be delivered to the Executive Committee for evaluation and actions.

2. Scientific report (in preparation) with the results of the second reliability test (performed by 7 adult and 7 child neurologists). The overall agreement at step 1 was poor both for adult and for child neurologists and improved at step 2 only for child neurologists; the results are still under statistical revision to check the consistency of the data with differing imputations. After this revision, the text will be circulated to the TF members for final comments and then sent to the Executive Committee.

**Status Epilepticus Task Force**

Chair: Shlomo Shinnar

The Epidemiology Commission Task Force on Status Epilepticus merged with the Commission on Classification task force on SE to create a unified clinical and epidemiological definition of SE. Meetings were held in London and in San Diego. A manuscript has been written and will be circulated to all task force members for comments this month. It is anticipated that the document will be submitted to the Executive in the next three months.

**Genetics Commission – Sam Berkovic**

**List of Commission Members:** Sam Berkovic Australia, Chair s.berkovic@unimelb.edu.au; Ruth Ottman USA, Past Chair ro6@columbia.edu Shinichi Hirose Japan hirose@fukuoka-u.ac.jp Thomas Sander Germany sandert@uni-koeln.de Peter DeJonghe Belgium peter.dejonghe@molgen.vib-ua.be Nigel Tan Singapore nigel.tan@alumni.nus.edu.sg Sanjay Sisodyia UK s.sisodyia@ion.ucl.ac.uk Dan Lowenstein USA lowenstein@medsch.ucsf.edu Marcello Kauffman Argentina marcellokauffman@marcellokauffman.info Alica Goldman USA agoldman@bcm.tmc.edu Carla Marini Italy c.marini@meyer.it Executive Committee Liaison Michel Baulac michel.baulac@psl.ap-hop-paris.fr

1) **Aims**

As above

Initiative #1: Improve genetic literacy of the 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.

2) **Commission activities from July 2012 through June 2013**

Initiative #1 a. EpiGAD has been regularly maintained, updated and audited.
In 1997 the WHO, ILAE and IBE decided to join forces in order to raise epilepsy to a level of awareness that had not been achieved ever before. This partnership is the ILAE/IBE/WHO Global Campaign Against Epilepsy – “Out of the Shadows”, with as its mission statement: To improve the acceptability, treatment, services and prevention of epilepsy worldwide.

In 2009, a Task Force was established with an aim to establish a strategic plan with action points to forward wider development of activities within the GCAE, and raise awareness of achievements. A strategic plan was finalised, with four main goals:
1. To improve the visibility of epilepsy and the activities of the Global Campaign in all countries
2. To promote activities of all epilepsy projects on a country and regional level
3. To assess and strengthen health care systems for epilepsy
4. To increase partnerships and collaboration with other organisations

It has become clear however that throughout the world there are many initiatives that could be interpreted as Global Outreach, for which there needs to be a raised awareness, but such activities are not necessarily directed through the collaborative efforts of the GCAE. The Task Force was therefore renamed that for ‘Global Outreach’ with a primary aim of raising awareness of global educational and service initiatives in epilepsy throughout the world.

Examples of activities that have been undertaken within the remit of the GCAE over the last four years have included:
1. Launching of the Global Campaign website in June 2010 at the European Congress in Rhodes, www.globalcampaignagainstepilepsy.org, with information about current activities, regional reports and updated information about demonstration projects;
2. Development of a new slogan for use worldwide ‘Stand up for Epilepsy’;
3. Demonstration Projects

Georgia: Completion of a Demonstration Project in Georgia in 2011. Demonstration projects remain a key activity of the Global Campaign Against Epilepsy. The general objectives are to reduce the treatment gap and social and physical burden, educate health personnel, dispel stigma with an ultimate goal of developing a variety of successful models of epilepsy control that can be integrated into the health care systems of the participating countries and regions and, finally, applied on a global level.

Honduras: A project is currently underway in Honduras with as its objective: to develop a sustainable, efficient and applicable strategy to address epilepsy at the primary health care level with supervision and support from the specialized system. This strategy will reduce the gap of access to diagnostic and therapeutic resources and improve health care and services for people with epilepsy.

Cameroon: Attempts are still being made to try and raise funds for a project in this country.

China: In China, where the Demonstration Project completed in 2004, the "Global Campaign" activities have, under the support of the Chinese government, extended continuously in rural area, and are now implemented in 135 counties of 18 provinces, totally covering 75 million population, 83,518 people with convulsive epilepsy are now on medication of phenobarbital and/or valproate acid, free of charge;

The possibility of further projects has been explored during this period. During the meetings between the Campaign Secretariat (Nico Moshe, Mike Glynn and Tarun Dua) and also Emilio Perucca, this was also discussed with Dr. Shekhar Saxena, Director of the WHO Department of Mental Health. Dr Saxena promised to actively try to raise funds for activities in the field of epilepsy. This would not have been possible in previous times as WHO was never allowed to take funds from the industry. The implementation and execution of projects comes under the Ministries of Health of the respective countries who will work closely with the WHO country offices. During the meeting of the Campaign Secretariat in October last year, the projects in Ghana and Viet Nam were discussed; these are being sponsored by Sanofi Espoir Foundation. Dr Saxena reported that negotiations with UCB were ongoing and this has led to this company sponsoring projects in Myanmar and Mozambique. An initial meeting has taken place in Myanmar with the participation of Dr. Byung-in Lee as the ILAE representative.

4. Completion of a model for assessment of epilepsy services and resources, piloted in Tajikistan, with plans for replication in two further European countries;

5. Regional reports on Epilepsy published in EMRO and EURO and launched at stakeholders meetings in the respective regions. Such reports have now been published in all regions of the world,

6. Stakeholder meetings were held in all regions with the participation of the national stakeholders and the regional and international IBE, ILAE and WHO leadership. In particular, specific initiatives have been undertaken:
   a. Within PAHO a strategic plan for epilepsy from the program for Mental Health and Neurological Disorders has been developed for implementation in Latin America. This has been signed by all Health Ministers in the Americas. On November 14th, 2012, the Pan American Health Organization (PAHO/WHO), the International League Against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE) signed a Memorandum of Understanding that bonds them in a 10-year-long partnership to deploy the Strategy and Plan of Action on Epilepsy for the American continent.
   b. There has also been the Institute of Medicine Report on Epilepsy with implications for the USA. It is unclear as to wider implications at present.
   c. Within Europe the European Taskforce on Epilepsy has been active, and a written declaration on epilepsy passed through European Parliament in 2012. A European Research Forum is planned for May 2013.

7. A C.D. has been produced on the history of the Campaign which will be available in Montreal, during the International Epilepsy Congress
8. The documents that had been developed within the project on Epilepsy and Legislation “Basic Principles for Epilepsy Legislation” (setting out basic principles and rights that should be considered when drafting legislation related to epilepsy) and the “Guidance Instrument for developing, adopting and implementing epilepsy legislation” were finalised and produced on c.d. This c.d. disseminated during the International Epilepsy Congress in Montreal, Canada.

9. A C.D. containing the history of the Campaign has been produced and will be available in Montreal as well.

10. Jointly published WHO guidelines on management of neonatal seizures, and contributed to the WHO MhGAP intervention guide for treatment of epilepsy.

11. Within the WHO mental health Gap Action Programme (mhGAP) ILAE contributed to the development of the chapter on epilepsy in the evidence-based intervention guide for the management of mental, neurological and substance use disorders in non-specialized health settings.

12. Within the 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, contributed to this project.

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

Neurobiology Commission – Jeff Noebels and Astrid Nehlig

Commission Goals

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

• 2011: WONOEP at Grottoferrata: “Finding a Better Drug for Epilepsy” a 3 day advanced workshop involving 77 scientists from academia and industry. Five “Critical Appraisals” covering each of the major themes of the workshop have been published in Epilepsia in 2012/2013.

• 2013: WONOEP in Montreal: “New Technologies to Study the Epileptic Brain” (about 60 scientists from academia and industry). Several “Critical Appraisals” covering each of the major themes of the workshop are planned to be published in Epilepsia in 2014.

• 2011: San Servolo course on Bridging Clinical and Scientific Research in Epilepsy 2011
An international 14 day residential summer school including young clinical and basic investigators from 55 countries.
During this course an innovative research project on neuro-malaria and epilepsy in Africa was identified. This project was led by a young and bright neurologist from Nigeria and was planned to be partly supported by NBC. The application was submitted to the Gates Foundation in 2012 for financial support but was not selected.

• NBC Symposium at IEC and EEC Congresses
- Epilepsy, Dementia/Alzheimer’s Disease and the Temporal Lobe (Rhodes EEC 2010)
- Metabolic mechanisms of epileptogenesis (Rome IEC 2011)
- Pediatric epilepsy syndromes: experimental models and therapeutic perspectives (London EEC 2012)
- Role of non-neuronal cells in epileptogenesis (Montreal IEC 2013)
- Future: continue organizing NBC symposia at each IEC and EEC, one is currently planned for Stockholm EEC 2014
• **2012: London Translational Workshop** to optimize and accelerate preclinical epilepsy discovery organized by the sub-commission on translational research was held in conjunction with the AES Task Force on Translational Research prior to the EEC meeting in London. Seven task forces were created:
  - Defining the clinical “gaps to care” and the “opportunities” to develop new treatment approaches for epilepsy
  - General technical and methodological issues in AET development
  - Issues related to development of new anti-seizure treatments
  - Issues related to development of anti-epileptogenic therapies
  - Issues related to symptomatic and disease modifying treatments affecting comorbidities
  - Issues related biomarkers and surrogate endpoints
  - Issues related to “Stage II pre-clinical trials” and criteria to propose candidates for clinical trials

  The proceedings of this workshop gave rise to one paper already published Epilepsia and 7 additional manuscripts are under review in Epilepsia.

• **Gordon Conference**, an international 5 day advanced neurobiology of epilepsy workshop on Mechanisms of epilepsy and Neuronal Synchronization taking place in Waterville, USA.
  - 2010: “Dynamics, Development and Dysregulation”
  - 2012: “Synchronization, Reorganization in the Epileptic Brain”

**Plans for the future include:**

- Continue organizing the WONOEP meetings at each IEC meeting (2015 and 2017) to gather the best scientists in a given domain of neurobiology to fertilize exchanges and disseminate knowledge.

- A joint project to be launched with the Education Commission which seeks to advance professional training in epilepsy with a focus on new research projects to solve regional epilepsy issues in less advantaged countries, like the neuro-malaria project in Africa.

- The development of a new course on the Neurobiology of the Epilepsies is planned in Asia for the next future. Associated with this a specific task force will be devoted to the identification of needs which once defined will take specific actions.

- Establish a catalog/list of laboratories and tools of valuable resource to allow training of scientists and clinicians from not so well developed countries. This project was not achieved during the present term of the commission for various reasons and will be developed during the next term.

- Neurobiology dissemination at meetings
  - Organization of basic science symposia in epilepsy meetings but also in less focused meetings (neurobiology, pediatrics, pharmacology)

**Neuropsychobiology – Andy Kanner, Marco Mula**

**List of commission members:**
Mike Kerr (UK), ES Krishnamoorthy (India), Frank Besag (UK), Bettina Schmitz (Germany), W. Curt LaFrance Jr. (USA), Lilia Nunez Orozco (Mexico), Naoto Adachi (Japan)

**List of subcommission:**
- 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:**
Mission of the commission is to ensure that health professionals, patients and their care providers have the educational and scientific resources that are essential in understanding, diagnosing and treating psychiatric and cognitive complications of patients with epilepsy.

**Commission activities:**

The commission continued the project of promoting translation and validation of screening instruments for depression in epilepsy. New versions of the Neurological Disorders Depression Inventory for Epilepsy (NDDI-E) have been validated in several languages and psychometric properties have been published. The NDDI-E is now available in validated versions for patients with epilepsy in the following languages: English, German, Italian, Spanish, Portuguese, Japanese and Korean. A French version and an Arabic version will be soon available.

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

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

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

The Task force on Therapeutic strategies published a consensus statement on the FDA alert about suicide during treatment with antiepileptic drugs.

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

The Task force on psychogenic non-epileptic seizures developed a specific document on diagnostic standards for PNES. The document will be soon available in Epilepsia.

**Accomplishment:**
- The NDDI-E translated and validated in seven languages
- Consensus statements on AEDs and suicide published in Epilepsia
- Diagnostic standards for PNES in press in Epilepsia
- Guidance of treatment of psychiatric disorders in adults with epilepsy published as Epilepsia Supplement (8 papers)
- VIREPA course on Psychiatric aspects of epilepsy

Projects to be finalized by the end of 2013:
- A consensus document on screening instruments for psychiatric disorders in adult patients with epilepsy
- Task force on Intellectual disabilities: one document to be finalized
- Task force on Child neuropsychiatry: eight documents to be finalized

Recommendation for further work:
Epilepsy is a complex disorder that needs a comprehensive approach. Psychiatric comorbidities represent an important obstacle complicating the management of patients with epilepsy and significantly affecting their quality of life and prognosis. Further work is needed to develop models for cost-effective interventions taking into account local specificities. The following aims have been identified as strategic:
- Close link with international psychiatric societies (APA, WPA, WFSBP)
- Identify geographical gaps and local needs
- Develop a consensus document on standard of care for presurgical and post-surgical psychiatric evaluation of patients with epilepsy

Pediatrics Commission – Perrine Plouin, Doug Nordli

• Autism and Epilepsy (Robert Tuchman)
  – We have increased awareness among the ILAE community regarding the complex relationship between autism spectrum disorders and epilepsy and the importance of identifying and treating social cognitive deficits as part of the comprehensive care of individuals with epilepsy.
  – We have put in motion projects to foster research on autism spectrum disorders and epilepsy.
• Epilepsy Surgery in Children (Helen Cross)
  – A review of the Diagnostic Test Utilization in Evaluation for Resective Epilepsy Surgery in Children has been performed, approved as an ILAE report and submitted for publication in Epilepsia with a flow chart of an evaluation protocol for presurgical evaluation
• The Infantile seizures task force is basically almost completed (Jo Wilmshurst)
  – data have been collected and analysed for most areas. I am in the process of going through the questionnaire from a final 890 global respondents
• Transition and Transfer(Jaime Carrirosa, Doug Nordli)
  – Questionnaires were handed out in North and Latin America.
  – Extensive review of literature was done.
  – Revision article was sent to Epilepsia
  – Oncoming work: Built up of pertinent questions. Search of published material to answer these questions. Construction of evidence based guideline
• Elearning pediatric programm (Monka Eisermann, Perrine Plouin)
  – 2nd edition is going on.
• San Servolo summer school (july 2012) “Management of seizures and epilepsies in neonates and infants”. (Federico Vigevano , Perrine Plouin)
  – 63 students from 44 countries; positive evaluation by students

Therapeutics Commission – Steve Schachter, Bernhard Steinhoff
The Therapeutics Commission has a broad mandate to review current treatments and to advocate for improvements. Because of the great diversity of the topics, ranging from the use of natural products to surgery, the Commission created separate task forces. Each task force will focus on a topic of growing interest or pressing importance: natural products, clinical trial strategies, pharmacogenomics and surgery.

Natural Products Task Force

*Steven Schachter, Chair*

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

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

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

New Strategies of Clinical Therapeutic Studies Task Force

*Jacqueline French, Chair*

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

Pharmacogenomics Task Force

*Patrick Kwan, Chair*

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

Surgery Task Force

*Bernhard Steinhoff, Chair*

The surgery task force has conducted a literature review of the surgical treatment of cavernomas associated with epilepsy, outlined recommended surgical approaches and identified opportunities for further research. A manuscript containing the findings and consensus recommendations has been sent for review prior to submission to *Epilepsia*.

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

Task force on Seizures and Epilepsy in the Tropics - Pierre-Marie Preux

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

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

Means:

- regular discussions through teleconferences or meetings
- establishing links with other ILAE task force or commissions
- enlisting the collaboration of experts depending on issues being addressed
- facilitating communication with other partners and institutions

Outcomes:

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

Results:

- Paper submitted on “Undue regulatory control on phenobarbital-an important yet overlooked reason for the epilepsy treatment gap-an urgent call for meaningful action”
- LASSE VII February 2013 (Sao Paulo, Brazil – E Cavalheiro) : Seizures and Epilepsies in the tropics
- Parasitel - Research proposal submitted to EU FP7 (but rejected): Parasites and epilepsy (PM Preux, and 8 european partners)
- ÉCLAIR – Research program on access to care in Cambodia and Laos (PM Preux)
- To be conducted:
  o Review of literature on the issue of prevention

Task Force on Definition of Epilepsy – Robert Fisher
A traditional, although not formally accepted, definition of epilepsy has been some variation of the following: “At least two unprovoked seizures occurring more than 24 hours apart, and after the first month of life.” This definition usually works well, but does not always correspond to a clinician’s view of when epilepsy is present. In 2005, a Task Force defined epilepsy conceptually as at least one unprovoked seizure and an ongoing predisposition for another (Fisher RS, van Emde Boas W, Blume W, Elger C, Genton P, Lee P, Engel J Jr. Epileptic Seizures And Epilepsy: Definitions proposed by The International League Against Epilepsy (ILAE) and the International Bureau For Epilepsy (IBE). Epilepsia 2005;46:470-472.). The meaning and quantification of such a “predisposition” was not provided in the Epilepsia publication. A special circumstance of reflex epilepsy also needs to be considered, since reflex seizures are by definition provoked. An additional important issue is whether epilepsy is forever. Do two unprovoked seizures at age 3 confer a lifelong diagnosis of epilepsy?


The discussion is ongoing, so the operational clinical definition below should be considered tentative and presently unofficial. It does not necessarily reflect the view of every member of the Task Force.

A Proposed Operational (Practical) Clinical Definition of Epilepsy

Epilepsy is a disease of the brain defined by any of the following conditions:

1. At least two unprovoked seizures occurring more than 24 hours apart, and after the first month of life.

2. One unprovoked seizure and a probability of further seizures similar to the general recurrence risk after two unprovoked seizures (approximately 75% or more).

3. At least two seizures in a setting of reflex epilepsy.

Epilepsy is considered to be no longer present for individuals who have remained seizure-free and off anti-seizure medicines for at least 5 (or 10 - debated) years, provided that there are no known enduring predispositions conferring a high risk for future seizures.

Different operational definitions apply in different circumstances. Therefore, there is no inconsistency with using the traditional definition for epidemiological or other studies. The impact of an expanded definition on people with epilepsy and other stakeholders will be discussed.

Task Force on Guidelines – Tim Pedley, Nathalie Jette, Jo Wilmshurst

Objectives: 1. Systematic review of published epilepsy related guidelines
2. Identification of gaps in guidelines
3. Recommendations regarding which guidelines need to be updated
4. Recommendations regarding process which should be followed in future epilepsy guideline development
5. How to effectively disseminate epilepsy related guidelines?
**Systematic review:** This task force has completed the search (7 databases and 6 grey literature sources) to identify epilepsy/seizure related clinical guidelines in all languages. 9766 abstracts have been screened in duplicate with 359 full text articles (13 languages) also screened in duplicate for eligibility. Data abstraction expected to begin summer 2013 and should be completed by fall 2013. Final report expected to be ready by end of 2013/early 2014.

**Guidelines Symposium:** Dr. Timothy Pedley is chairing a symposium called: “Guidelines: the good, the bad and the ugly” at the IEC in Montreal. Speakers include:

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

**Dissemination of results/End of term plan:** The current work of the guidelines task force just began this past year and will be ongoing through 2013. Future plans and activities to be discussed at the IEC face to face meeting in June 2013. Dissemination of results for initial activities is anticipated through manuscript submission to Epilepsia, and presentation (venue to be determined).

**Task Force on Reports and Position Statements – Ed Bertram**

**Members**
- Giuliano Avanzini
- Edward Bertram
- Fernando Cendes
- Sheryl Haut
- Sunao Kaneko
- Shih-Hui Lim
- Gary Mathern
- Cigdem Ozkara
- Ingrid Scheffer
- Philip Schwartzkroin
- Michele Simonato

**Goals**
- Establish guidelines for League official positions for scientific and clinical papers
- Develop process for reviewing and approving official positions
- To align reports with Strategic Plan goal of maintaining League’s position as epilepsy thought leader

**Task Force Recommendations: Two Types of League Publication**

**Official Position**
- Limited number (e.g. classification, definition)
- Created with prior approval of EC
- Extensive public review
- Process for adding comments
- Final approval by EC as an official position

- **League Approved**
- Reviews created by League commissions and task forces
- Prior approval before creation not needed
- Papers reviewed by Epilepsia
- Designation as League Approved by EC following review of editorial comments

**Task Force on Sports and Epilepsy – Pippo Capovilla**

**List of Members**

Chair: Pippo Capovilla (Italy)
Members: Ricardo Mario Arida (Brazil)
Alexis Arzimanoglou (France)
Terry O’ Brien (Australia)
Ken Kaufman (USA)
Najib Kissani (Morocco)

**Mission**
The TF was born in July 2011. Two main goals were posed for the activity of the TF.  
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.

**TF Activities from July 2011 through July 2012**
TF Meetings were in Rome IEC and Baltimore AES. The main activity of the TF 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 medallists. They have been presented in an exhibition at the recent ECE in London.

**TF Future activities**
1. To increase the visibility of the Photography Sport Project having the participation of other famous top level sport personalities.
2. To prepare 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 delegated 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

**Task Force on ICD-11 - Ettore Beghi – report not available**

**Task Force on Stigma – Nathalie Jette**

**Objectives:**

1. To carry out an up-to-date international systematic review focusing on epilepsy-related stigma: Tools to measure it, frequency and nature of stigma, and interventions to address it.
2. To make recommendations regarding gaps and future research needs in the area of epilepsy-related stigma
**Systematic review:** The Stigma task force has screened 4123 abstracts in duplicates from 13 databases (all languages), reviewed 821 articles to determine their eligibility for data abstraction and have completed the initial data abstraction (study demographics/region, topic addressed, age groups, etc.) for just over 300 articles (38 addressing tools used to identify stigma, 284 addressing the frequency and nature of stigma and factors associated with it and 28 addressing interventions for stigma). Data abstraction began in March 2013 with initial results to be presented as a platform session at the IEC in Montreal in June 2013. Full data abstraction in duplicate is expected to be completed end of 2013 with several manuscripts/reports to be written early 2014.

**Stigma Symposium:** ILAE meeting, Montreal 2013. The symposium proposal submitted jointly by NAC and the Commission on Stigma was accepted for the upcoming Montreal meeting, chaired by Dr. Jette. 

*Main Session: Stigma in epilepsy - who, why and what to do? Speakers:*

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

**Dissemination of results/End of term plan:** The current work of the stigma task force will be ongoing through 2013 and early 2014. Dissemination of results is anticipated through manuscript submission to Epilepsia (3-4 manuscripts), and presentation at the symposium in Montreal 2013.

**Constitution Task Force – Tatsuya Tanaka**

**Achievable Project:**

Through frequent meetings of the Constitution Task Force Members (Drs. Michel BAULAC, Marco T MEDINA, Simon SHORVON, Samuel WIEBE and Tatsuya TANAKA) during past four years, a final amended version has been finalized with a number of changes to the ILAE Constitution. The major amendments were targeted to the structure of the League and responsibilities of its officers. The proposal of Constitution Amendment by the Constitution Task Force was approved by the Executive Committee Meeting on March 26th 2010 in Ghent.

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

Following ratification of the amended constitution, League’s By-Laws were also amended by frequent meetings of the Constitution Task Force and Executive Committee members, according to the amended constitution. Thus, Amended By-Laws were ratified by the Executive Committee on October 2nd, 2011. The amended By-Laws 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 for their devoted efforts in order to accomplish these hard works during past 4 years.

1. **Retrospective verification of the amended Constitution**
   It is important to verify whether the amendment of the Constitution and By-Laws are well adapted to the League, in the practical use. The League has elected its new President and Executive Committee Officers for 2013-2017. The Constitution Taskforce paid particular attention in order to detect any remaining inconsistencies or ambiguities.

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

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

Goal 2 was for the ILAE to serve as an international information resource and leader for optimal, comprehensive epilepsy care. There are four aims under this goal: work with local organizations, Regional Commissions, and partner organizations like the IBE and the WHO through the Global Campaign Against Epilepsy, promote and facilitate initiatives for broad standards of comprehensive epilepsy care, to interact with governmental groups in establishing the needed resources and to enable all health care professionals to have an active relationship with ILAE.
Again, the ILAE has made substantial progress during the current EC. The Global Campaign Against Epilepsy was re-assessed and became the Global Outreach headed by the Presidents of ILAE and IBE. Over the past four years, the ILAE has participated in regional initiatives about epilepsy care. The League was involved in the 2012 publication of the US Institute of Medicine report on epilepsy, the Pan-American Health Organization plan to improve care throughout the Americas, and the European Initiative with the Written Declaration on Epilepsy. The ILAE continues to work with like-minded organizations such as Vision 20/20 in North America. One of the more exciting initiatives was to link sports figures with persons with epilepsy through the Sports and Epilepsy Task Force (G. Capovilla, Chair) to encourage sports participation by people with epilepsy. The League supports improved communications with continuous evolution of our website to make it more useful and user friendly. The African Commission was a major component of this goal.

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

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

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

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