

INTERNATIONAL LEAGUE AGAINST EPILEPSY

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Commission Chair Meeting Report Friday, December 2, 2011 – Baltimore, MD

Gary Mathern convened the meeting at 8:15 a.m. He reminded everyone that there are 18 months left in the term and the goal of this session is to discuss the projects that each commission expects to be completed by the end of the term, including what Challenges might be faced. In addition, the Executive Committee would like to hear what plans commissions have for disseminating the results of their projects, including any public message that should go out.

It was announced that the Executive Committee has voted to have official position papers of limited number, the process for which is being determined. For definition/guideline/recommendation papers by experts groups the Executive Committee would like to be communicated with as to the purpose, scope and audience. Jack Pellock also welcomed the Commission Chairs to the AES meeting and thanked them for their work in achieving the League's mission.

Commission Reports

Global Outreach Task Force – Helen Cross, Shichuo Li, Hanneke de Boer

Helen Cross opened by explaining the reasoning for the change from Global Campaign to Global Outreach, which better reflects the broad reach of league activities. She reviewed the progress of activities within each of the goals of the Action Plan:

- Goal 1: Raising Awareness
 - Development Slogan: “Stand up for Epilepsy”
 - Newsletter: 1st issue Electronic Newsletter – August 2011
 - CDs: No. 1 - Selected publications
 - Publication articles on activities: IENews, Epigraph, WFN Newsletter, Lancet
- Goal II: Promote activities at country and regional level
 - Regional reports on implementation
 - Stakeholder meetings AMRO, EURO
 - Demonstration projects – Georgia complete
- Goal III: Assess and strengthen health care systems
 - Resource assessment and tool development Tajikistan
- Goal IV: Increase partnerships and collaboration
 - Institute of Medicine
 - WHO-mhGAP forum
 - European Brain Council

The Task Force will focus on the following in the last 18 months:

- Communicate activities
- Newsletter 3x/year
- Health system assessment in two more countries
- Task force for stigma in epilepsy to complete systematic review

- Stakeholder meeting Asia/Oceania
- Aid in implementation plans for PAHO, EURO, IOM

Challenge:

- Receiving information about what is going on worldwide
- Ensuring effective and timely communication goes out about what Global Outreach is doing.

Nico noted that with epilepsy being recognized as the only disease in the MH Gap program and the PAHO and EURO initiatives, ILAE is uniquely placed. Collaboration and communication will be important.

Education Commission – CT Tan

CT reviewed the educational activities of the Commission implemented by regional commissions:

- workshops
- summer schools
- congresses and proceedings
- visiting professors/fellows programs
- EEG certification

There are other activities working directly with topic-oriented commissions:

- online education via VIREPA, e-textbook, congress and workshop recordings
- educational program in IEC
- educational journal (under discussion)

Challenge:

- Increased costs for VIREPA in 2012 due to new courses and need for additional personnel.

Commission on African Affairs - Amadou Gallo Diop

Gallo Diop opened his presentation by pointing out the high prevalence of epilepsy and huge treatment gap in Africa. He reviewed the commission's outcome goals in three areas:

Training

- Identify centers with training capacity.
- Identify teaching resources
- Hold educational meetings
- Visiting professor initiative

Communication and Advocacy

- Quarterly news report
- Update GCAE document in French, English, Portuguese

Research

- Generate publications
- Focused research
- Monitored progress
- Neurology directory
- Research database

Gallo noted that resource restrictions, the African Commission is focused on interfacing with other groups with common interests/agendas in Africa including IBE, IBRO SONA, EFNS, Pan Arab Union of Neurological Societies, WFN/PAANS, ICNA /ACNA, WHO. A plan is being developed for a 2 day meeting with many of these organizations to discuss project coordination and avoid gaps and redundancy of efforts.

Challenge:

- Developing appropriate resources to accomplish the commission's mission.
- Effectively communicating with and coordinating and integrating the efforts of the different groups mentioned above

Gary Mathern congratulated the Commission on all the work it has done in its first year of existence. He also noted IBE's valuable involvement.

Commission of Asian & Oceanian Affairs - Byung In Lee

Byung In Lee reviewed the Commission's achievements and future plans within the context of the Commission's Action Plan:

Action Plan 1 - CAO A Website and Newsletters

- CAO A-Website
- Organization of Information committee
- Publication of CAO A Newsletter

Future plans

- Optimal management of CAO A-Website
- 1st CAO A-Newsletter will be published in 2012

Action Plan 2 - Enhance Education and Training in Epileptology

- ASEPA
 - Teaching courses and workshop, EEG Exam: Part I & II, Publication of AOEC Proceedings, Fellowships
- Epilepsy Summer School

Future plans

- More target-oriented teaching programs
- Promotion of ASEPA-Chapter interactions

Action Plan 3 - Stimulate Clinical and Translational Research

- Organization of RTF
- Scope of action
- CAO A-research priority document underway
- Pre-congress basic research program at AOECs in collaboration with ASEPA

Future plans

- Approval of CAO A-research priority document in 2012
- Prepare the Registry of researchers and research centers in AO region for research network
- Initiate or promote patient registry systems of AO region
- Initiate or promote collaborative regional research projects

Action Plan 4 - Facilitate Global Campaign Against Epilepsy (GCAE) Activities

- Define role of GCAE-TF
- Continuing support of Lao and E Timor's projects

Future plans

- Organize GCAE-TF Activities to accomplish the defined role

Action Plan 5 - Organize the AOEC every 2 yrs

Action Plan 6 - Initiate the "Asian and Oceanian Outstanding Achievement Epilepsy Award"

Action Plan 7 - Facilitate interactions with local chapters and other epilepsy organizations of the region

Future Plans

- Promote regular involvement of CAO A/ASEPA in programs of other epilepsy

- organizations in the region
- Promote establishment of Epilepsy Surgery TF and pediatric Epilepsy TF in collaboration
- Promote CAO/ASEPA programs in annual congresses of each chapters
- Continuing support for the Regional Epilepsy Summer School

Action Plan 8 - Promote New Chapter Formation

Future Plans

- Myanmar and Cambodian chapters in next IECs (2013)
- Papua New Guinea, Laos, Bhutan, E Timor in next stage

Byung In Lee commented that interregional collaboration such as joint symposia at regional congresses is under consideration.

Challenge:

- Effectively communicating and collaborating in a region with a wide diversity of cultures, languages, nationalities.

Commission of Eastern Mediterranean Affairs – Michel Baulac for Ahmad Beydoun

The region is clearly in great political turmoil and so the activities of the Commission are greatly hindered. There are, however bright spots and achievements including:

- Successful implementation of the 1st Annual Saudi Epilepsy Society Symposium
- Some attendance from the region at WFN
- New chapter request from Kuwait
- Evolution in the UAE Chapter, Chair has changed (Pr Saadi)
- Survey in Lebanon on New Onset Epilepsy Lebanon

It was noted that Turkey is in a crucial place for reaching out to the region through education.

Charge: Develop an alternate way to provide education that doesn't exclude the regional commission but uses countries close by like Turkey.

Commission of European Affairs – Meir Bialer

Meir Bialer reviewed the Commission's achievements and future plans.

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

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

- EUREPA continues as the European Educational Academy within the CEA
- Established an educational agenda with procedures for application for CEA support on the CEA website
- Continuing with the Migrating Courses in 2012/13
- Coordinating the European Educational Courses
- Welcome new regional courses

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

- Extensive dialogue via (EAE) with EU executives lobbying via various ILAE-Chapters aiming to give epilepsy research priority in EU funding – Written Declaration
 - It was noted that the involvement of all the chapters as well as IBE's participation made the Declaration possible. The energy and momentum the collaboration created has continued and borne fruit.
- CEA-EU Symposium
- Support scientific conferences with European added value that publish post-conference proceedings

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

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

- CEA-CNA-CTA joint task force (JTF) on regulatory issues of new AEDs (meeting in Rhodes, AES, Rome)
- JTF-EMA-FDA meeting on regulatory issues with a possible continuation at the London-ECE

Aim 6- To help ensure that ILAE's organizational structure is efficiently & effectively dedicated to fulfilling ILA mission

- Continuous update of European chapters' chairs & secretaries
- Establish ILAE chapters in the 3 remaining European countries
- Update CEA rules in accordance with the ILAE-EC proposed constitutional amendment

Meir noted that the Commission has learned that:

- There is great value in working with politicians to advocate for epilepsy education and research
- Move resources from more developed areas to less developed ones
- Collaboration is key

In light of these lessons and previous discussions in the day, the idea of a Pan Mediterranean Epilepsy course, a joint venture between the European, African and Eastern Mediterranean, was discussed as an activity worthwhile to consider.

Gary asked if the Commission had thought about capturing the content from the many educational activities in which they are involved. Meir noted that though the Commission has no immediate plans, it is certainly open to the idea.

Meir noted that the Written Declaration on Epilepsy is an idea that could be exported to other regions. Byung In Lee stated that in his region there is a strong stigma against epilepsy in most countries. Yet there is no central political entity like the European Union to assist in pushing forward such a regional declaration and so it would need to be done country by country. He encouraged the CEA to propagate the idea of the declaration for individual countries as an example for other regions.

Stand Up For Epilepsy – Pippo Capovilla

Pippo Capovilla shared information about Stand Up For Epilepsy (SUFE), a project that the Sports in Epilepsy Task Force is coordinating. The aim of SUFE is to create a collection of images of famous sport persons with children or teenagers with epilepsy to 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. Twenty volunteers representing 16 countries are currently involved and participation from other chapters is being solicited. The first set of photographs has been submitted and a number of other sports figures have already agreed to be photographed or have agreements under negotiation. The Commissions can assist by promoting the project utilizing the literature provided at the SUFE Web page and by keeping the Task Force informed. Further development of SUFE could include an expansion of the project to other fields such as the arts.

Commission on Latin American Affairs – Manuel Campos

Manuel Campos discussed the Commissions activities of the past year and recommendations for the future.

- Strategy And Plan Of Action On Epilepsy
- V Latin American Summer School on Epilepsy (LASSE). February 2011, Sao Paulo, Brazil.
- Latin American Academy of Epilepsy (ALADE)

- Epilepsy Fellows for Latin-Americans in Latin America.
- Relationships north America sub-commission
- New ILAE chapters in Latin-America
- Work together with IBE

Future Plans

- Support the Strategy and Plan of Action on Epilepsies for the Americas (main emphasis for future)
- Support to LASSE as an important educational activity.
- Support to the Latin American congresses, as the main activity in our region (Quito 2012).
- Continuous support to the Latin American Epilepsy Academy (ALADE) and the regional educational activities.
- Support the Epilepsy Fellow for Latin-American in LA

The successful Epilepsy Fellows for Latin Americans in Latin America program is a model worth considering exporting to other regions like Africa.

Challenge/Charge:

- Each ILAE and IBE chapter will need to work together to develop a relationship with the local government.

Commission on North American Affairs – Sheryl Haut

Sheryl Haut reviewed the accomplishments and future plans of the Commission within the context of the ILAE's Strategic Plan.

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
- Translation project - pilot Spanish translation of 2 symposia at AES, expansion to be explored
- 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
- Telemedicine
- International symposia/courses
- Regulatory affairs
- Neuro-cysticercosis prevalence project – manuscript in late 2012

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

- IOM report – dissemination of recommendations
- PAHO initiative – implementation will be a major focus for the NAC during the remaining 18 months of the term.
- Formation of the Epilepsy Society of the Caribbean

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

- Travel support
- Website development

Challenge

- Incorporating the work of topic-oriented commissions
- Disparities study needs to be done

Charge

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

Neuropsychobiology – Andy Kanner

Andy Kanner reviewed the accomplishments and future plans for each of the Commission's Task Forces.

Task Force on Mood and Anxiety Disorders

- Translation into multiple languages and validation of screening instruments for major depression in adults with epilepsy.
Next two years
- Gather prospective data on the impact of applying the screening instruments to treatment of comorbid depression and anxiety disorders.
- Finalize algorithm on the pharmacologic treatment of depressive and anxiety disorders in epilepsy
Next three years
- Submit to Therapeutic and Regional Commissions

Education Task Force

- Development of course on Psychiatric Aspects of Epilepsy for Epileptologists for VIREPA.

Task Force on Psychiatric Aspects of Epilepsy Surgery

- Develop protocols to screen for the most common comorbid psychiatric disorders during pre-surgical evaluations.
- Develop protocols to identify and treat the most frequent post-surgical psychiatric complications (e.g., depressive with and without anxiety disorders) in the first post-surgical year.
Next year
- Submit proposal to Therapeutic and Epilepsy Surgery Commissions

Task Force on Psychiatric Comorbidities in Children with Epilepsy

- Identification of screening instrument of depression and anxiety disorders in children with epilepsy (Joan Austin, PhD, Rochel Caplan, MD and David Dunn, MD).
- Development of protocols on the use of psychotropic drugs in the treatment of depression and anxiety disorders in children with epilepsy.
- Development of protocols on the use of psychotropic drugs in the treatment of Attention Deficit Disorders in children with epilepsy.
Next two years
- Work with pediatric commission on the implementation of these proposals.

There was discussion about the challenge of education/raising awareness of psychiatrists. It was noted that the PAHO initiative and MH Gap project may help increase awareness. Additionally, the incoming APA President is a member of the IOM committee.

Charge:

- Bridge the education gap with psychiatrists/neuropsychiatrists.
- Identify where in the world efforts should be targeted.

Classification Commission – Ingrid Scheffer

The new organization of the epilepsies has been disseminated via Epilepsia and education globally (live and electronic) resulting in much debate and some modification in response to feedback. The Commission is seeing acceptance of the new terminology in papers using the new terminology and reviewers requesting the information.

2012

- Further refinement of organization in response to comments, translation to more languages, more education, encouraging each region to have a classification activity

Classification of Epilepsy Syndromes Task Force

- Diagnostic manual development for common and new syndromes with videos for each syndrome and EEG correlates.

2012

Develop and go live with Diagnostic Manual Website

Classification of Status Epilepticus Task Force

- Document to be developed from workshop at Status Colloquium at Oxford

2012

New status classification to be published

Challenge/Charge:

- Listen for refinement input
- Encourage people/other countries to work with the new organization
- Interplay of new organization and ICD coding (further discussion during Epidemiology Commission presentation)

Diagnostic Methods Commission – Fernando Cendes

Fernando Cendes reviewed the accomplishments and future plans of the commission and its five Task Forces noting that many of the activities involve working with other regional or topic-oriented commissions.

In conjunction with Education Commission, the commission is supporting the planning and implementing of e-learning imaging and EEG courses, as well as other educational activities in different part of the world, such as in activities during Regional Congresses and Latin-American School of Epilepsy (LASSE).

- FCD Taskforce - proposal for a new neuropathological classification system for FCD
- Neuropathology Task Force - proposal for a semi-quantitative ILAE scoring system for HS in epilepsy patients
- Neuropsychology Task Force
 - Summarize and advance evidence based neuropsychological practice.
 - Focus on relevance for clinical practice and directions for the future.
 - What are the important evidence based outcomes and their implications for improving diagnosis and clinical care?
 - What remains to be determined through future research to advance treatment?
- Neurophysiology Task Force –
 - proposed force to develop optimal guidelines for "MRI negative" cases in conjunction with the Pediatric Surgical Task
 - working on a retrospective study to define the utility of various tests in this cohort.
 - hope to incorporate some of the "MEG guidelines" and integrate our efforts with the imaging task force.
 -
- Neuroimaging Task Force –
 - consensus paper on the use of advanced and functional imaging methods
 - define the role of advanced structural and functional imaging methods in presurgical evaluation guidelines for children and adults, jointly developed and led through the Neuroimaging and Neurophysiology Task forces and the Paediatric Commission

Epidemiology Commission – Dale Hesdorffer, Ettore Beghi

A review of the commission's accomplishments and future plans include:

- Publications
 - Epilepsia supplement published (Standards for epidemiological studies and surveillance of epilepsy)
 - Combined analysis of SUDEP (Combined analysis of risk factors for SUDEP and Do antiepileptic drugs or generalized tonic-clonic seizure frequency increase SUDEP risk?: A combined analysis)
- Co-morbidity Task Force
 - Systematic review of epilepsy comorbidities
 - Formulated literature searches in OVID Medline and PSYCH INFO
 - Literature searches completed for psychiatric and cognitive
- Mortality Task Force
 - Systematic review of mortality in epilepsy with a focus on preventable causes of death
 - Further analysis of SUDEP risk
- Reliability Task Force
 - Reliability of different seizure type, etiology and syndrome classifications
 - Case reports assembled and more in process, particularly in pediatrics
 - In discussion with Classification Commission re: using case reports as an educational resource
 - Sample size needs calculation being undertaken by Dr. Logroscino
 - First reliability work to be done by the task force, second to be done in a selected group of neurologists
- Status Epilepticus Task Force
 - To develop an epidemiological definition of SE

Future plans for remaining 18 months include:

- Complete
 - The systematic reviews in comorbidity and mortality
 - Additional SUDEP paper
 - Conduct reliability test of the epilepsy classifications
 - Create an epidemiological definition of status epilepticus
 - Hold a symposium/workshop on
 - The standards supplement
 - Preventable causes of death in epilepsy

There was a broad discussion about incorporating the new classification organization into the new ICD-11 codes and whether a reliability study was needed. Ettore Beghi noted that WHO has a timeline for the formation of the ICD codes. Ingrid Scheffer expressed concern that it is too soon to focus on the classification organization. It was concluded that the integration of ICD coding with the classification organization needs to be well thought out and clearly communicated. Dialogue will be needed; there will be a process of acceptance of the change. Beghi replied saying that ILAE entrusted Donna Bergen, Marco Medina and himself to accomplish this task and the group identified an advisory board (represented by experts in the field including Ingrid Scheffer) which was periodically informed on the ongoing process and asked to provide constructive criticisms on the new ICD codes. Beghi informed the audience that a formal study is in preparation with the participation of the task force members to test the reliability of the ICD codes in their present version.

Genetics Commission – Sam Berkovic

Sam Berkovic noted that the commission's accomplishments and focus include:

- Improve Genetics literacy (professional)
 - GeneTests website. The Commission has negotiated with this important site to update and re-organize the information on Epilepsy. This will be of use to neurologists, medical geneticists and counselors for comprehensive information on epilepsy genetics

- Report on SCN1A testing (Shin Hirose) is being prepared for Epilepsia
- EpiGAD website is functioning well and is regularly updated. This is mainly of use for researchers
- Improve awareness and knowledge – destigmatization of epilepsy (public)
 - Information pamphlet
 - Interact with Global campaign
- Synergize Research
 - ILAE Consortium on Complex Epilepsies. A number of successful teleconferences have been held, a Charter has been developed and signed by all major groups and a face-to-face meeting is planned in March 2012

There was discussion regarding the importance of the educational applications for de-stigmatization of epilepsy for both professional and the public.

Neurobiology Commission – Jeff Noebels and Astrid Nehlig Jeff Noebels stated that the commission is 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. These include the following training workshops (in the past and forthcoming year):

- WONOEP 2011 at Grottoferrata, entitled “Finding a Better Drug for Epilepsy” a 3 day advanced workshop involving 77 scientists from academia and industry. Four “Critical Appraisals” covering each of the major themes of the workshop will be published in forthcoming issues of Epilepsia in 2012.
- 2011 San Servolo course on Bridging Clinical and Scientific Research in Epilepsy. An international 14 day residential summer school including young clinical and basic investigators from 55 countries.
- Symposia on epileptogenic mechanisms of tumor biology and metabolism at IEC, Rome 2011
- 2012 London Translational Workshop on Improved Preclinical Models for AED Drug Testing organized by the subcommission on preclinical research will be held in conjunction with the AES Task Force on Translational Research prior to the EE meeting in London. The proceeding of this workshop will be published as a followup to the report from both groups in Epilepsia (2011)
- 2012 Gordon Conference on Basic Mechanism of Brain Synchronization, Waterville, USA An international 5 day advanced neurobiology of epilepsy workshop

Plans for the future include:

- An innovative research project on Neuro-malaria and epilepsy in Africa arising from the San Servolo Course, the application for which is being submitted to the Gates Foundation in 2012.
- 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.

There was a brief discussion on the issue of how to make findings in the neurobiology of epilepsy more relevant for a clinical audience. One view is that relevance can be emphasized by carefully choosing the best speakers for educational activities, partnering basic investigators with clinicians to ensure the translational research content is included and that basic research is contextualized. There was concern regarding the benefit and challenge of including basic science in clinical meetings. At issue is whether the ultimate goal of the ILAE Congress is to be a leading ‘disease meeting’ that integrates both clinical and scientific advances in the field similar to those designed by European, Asian, and American epilepsy societies, or is rather to be a predominantly ‘clinical meeting’. If the former is indeed the goal, congress planners might also explore how to enhance the relevance of clinical findings to basic scientists in order to better balance the program and audience.

Charge:

- Think through how neuroscience can be better integrated with initiatives like PAHO, and IBRO-initiated training activities, particularly in Africa.
- Explore what role neuroscience can play with ILAE partners like IBE
- Continue to work collaboratively with other Commissions to integrate scientific and clinical training.

Pediatrics Commission – Perrine Plouin

Perrine Plouin reviewed the accomplishments and future plans of the commission and its Task Forces:

ILAE-AS Collaboration Taskforce

- Global Awareness of Epilepsy-Autism
 - AS-CURE-ILAE: *Scientific Research Synergies from a Global Perspective: Key Points*
Brooklyn, December 10, 2010
- Clinical Resources Survey

Goals for 2012

- Continue to develop comprehensive clinical resources for children with epilepsy and autism
- Raise awareness of screening for autism and related disorders in epilepsy clinics
- Continue to develop the infrastructure needed for research programs on epilepsy-autism at a local, regional, and global level

Adolescent Transition Task Force – mission is 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.

Recommendations for future work:

- Fall 2010/Winter 2011 – Pilot 5 step transition program at Children’s Memorial Hospital Epilepsy Center in Chicago
- Spring/Summer 2011 - Develop educational series via podcasts for providers about transition to adult care
- Summer/Fall 2011 - Recruit 6-10 sites internationally to pilot transition program
- Winter/Spring 2012 – Pilot transition program internationally
- Summer 2012 – Evaluate transition program via survey to providers
- Fall 2012 – Write summary of recommendations for transition to adult healthcare for pediatric patients with epilepsy

Pediatric Epilepsy Surgery Task Force

- To complete recommendations on the utilization of diagnostic tests in respective epilepsy surgery evaluation
- To complete the project on MRI negative cases (with diagnostic commission)
 - Prospective multicenter study of relative role of differing investigations in assessment of MRI negative cases
- To further complete recommendations on
 - surgical strategies
 - evaluation of outcome

Guidelines for the Evaluation of Infants with Epilepsy Task Force

- Will include recommendations for genetic testing, metabolic investigations, electrophysiological studies, imaging and screening for autism in infants in collaboration with the autism task force. The task force is making steady progress with the next meeting to be held prior to the European Epilepsy Congress in 2012.
- Future plans could include dissemination of the guidelines at regional meetings as well as web-based resources.

It was noted to avoid the use of the term “guidelines” since the recommendations will not be evidence-based.

Development of distance education course on Neonatal and Pediatric EEG in collaboration with Education Commission – 35 students from over 20 countries are currently participating in the VIREPA course.

San Servolo Summer School - July 2012 – will focus on neonatal and pediatric epilepsies.

Charge :

- Develop better integration with Neurobiology Commission to open communication and awareness for neonatal and pediatric epilepsies among basic scientists
- Develop dissemination plans for commission's work particularly to regional commissions where the focus tends to be more on adults.

Therapeutics Commission – Bernhard Steinhoff

Bernhard Steinhoff reviewed the recent activities and future plans of the commission and its Task Forces.

Behavioral Treatment Task Force

- Actively explore opportunities to test the feasibility and preliminary benefits of a behavioral approach to epilepsy treatment in a developing region.
 - potential collaboration with Guangzhou Children's Hospital in Guangdong, China

Treatment Gap Task Force

- Proposal to re-visit the definition of the treatment gap by planning a workshop to achieve consensus on the definition of the coverage gap, causes of the treatment gap, indicators to measure the coverage gap, methods for integrating these metrics into existing country-specific information systems, and the need for further epidemiological studies.
- Regulatory issues: Re-availability of Phenobarbital – identify barriers to use, strategies to improve availability

Surgery Task Force

- Project to define a consensus on surgical treatment in case of cavernous angioma
- Project to develop guidelines regarding minimal standards for presurgical workup and surgical treatment of epilepsy
- Implement appropriate liaison with newly formed European Epilepsy Monitoring Association

Natural Products Task Force

- The botanical wikipedia is now being installed on the ILAE server. Once installed, the Wiki will be shown to ILAE leadership and, if approved, hosted on the ILAE Website or Therapeutic Commission site and thereby become a widely accessible resource for neuroscientists interested in the potential application of plant-derived products to developing new therapies for epilepsy.

Pharmacogenomics Task Force

- Meeting to discuss phenotype definitions has been planned Dec 2011.

New Strategies of Clinical Therapeutic Studies Task Force

- Meeting between the EMA and FDA in Paris in November 2011 to discuss the concept of abolishing the need for a monotherapy indication for epilepsy, and acceptance of a novel trial design (time to event).
- A white paper to address the proposal for a unified (both monotherapy and polytherapy) claim is underway.
- For the time to event initiative, the Task Force has sent letters to 8 pharmaceutical companies, requesting a post-hoc analysis of existing trial data to determine whether this approach would have been successful, and to determine the optimal outcome measures for the trial. So far, 3

companies, (representing trials from 5 drugs) have approved the proposal, and the others are considering the proposal.

Drug Task Force has to be reorganized.

Bernhard noted that there has been discussion regarding the need for a Brain Stimulation Task Force.

Challenge: Networking effectively with commission members with full work schedule.

Video Presentations – Ed Bertram

Ed Bertram stated that ILAE has created two sets of videos he would like to get opinions on prior to making them publically available.

Rome videos – Ed noted that at the Rome IEC, several speakers agreed to do a 3 minute video summarizing their presentation. The rationale for creating these videos was to make available some of the presentations from the international congress quickly and in a web friendly format to allow the content to be more widely distributed. One of the videos was presented and there was some preliminary discussion regarding their value.

Knowlera videos – A set patient/primary care oriented videos were created as a trial venture. Ed noted that it has been discussed for a long time using video educational material directed at patients and primary care providers, to give them some very basic but key information about epilepsy and the issues faced by people with epilepsy. Because of the target audience (lay public and professionals with little knowledge of epilepsy) and the web format, the presentations were kept simple with little attempt at nuancing the message. Ed stated that there has been discussion about dubbing them in other languages for posting on the ILAE web site or distribution to appropriate chapters. One of the videos was presented and there was some preliminary discussion regarding their value.

Charge to Commission Chairs: All the videos will be sent out for review. Specific feedback regarding their value is requested by January 10.

ILAE Website – Jean Gotman

Jean Gotman noted that the newly redesigned, more easily navigated Website and new commission Websites were launched in August. Jean asked that out-of-date or incorrect information be pointed out. Accomplishments since then include:

- Web Manager hired to maintain the web site
- Created structure to post videos, including good quality streaming. A few videos already posted, more to come
- Work being done to improve likelihood that ILAE web site is found by search engines (current state very poor)
- Web-based form created to request document to be posted on ILAE web site (vetting process for all requests)
- Creation of reference manual to guide each commission's assigned Web Editor, who will be charged with maintaining and editing their commission site. Staff gave a short demonstration on editing a commission Website.

The suggestion was made to consider adding a section on the Website for interesting journals and abstracts relating to epilepsy.

Epilepsia – Phil Schwartzkroin

Phil Schwartzkroin reviewed procedures for submitting commission reports to Epilepsia. He noted that brief reports of 500 -1,000 words would be in Gray Matters. No peer review is done.

Longer reports, i.e., critical reviews, research reports and supplements over 4,500 words, will go in a section of the journal called Special Reports. Phil reminded the group that supplements need to be financially supported by a commission budget and so should be included in the budget application.

Budget Process – Emilio Perucca

Emilio thanked everyone for submitting their budgets. The plan is to have final approval on January 15. The Strategic Planning Task Force will meet in Baltimore so that reviews of the budgets can be accomplished.

Closing Remarks – Gary Mathern, Nico Moshé

Gary Mathern stated that the purpose of the Commission Chair meetings has been to improve communication between commissions and with the Executive Committee. He noted that progress has been made over the past year as evidenced by the reports of collaboration and interaction among the commissions. He emphasized that continued communication and collaboration is important. Gary also noted that dissemination of information about the work being done by the commissions should not just be within ILAE but also to the rest of the world. A reminder was given that all work should be submitted to *Epilepsia* first before submitting elsewhere.

Nico Moshé expressed the appreciation of the Executive Committee for the hard work and time spent on the many commission activities reviewed during the day and for responding to many tough questions. He noted that the Executive Committee is very proud of all that the commissions have accomplished.

The meeting was adjourned at 4:45 p.m.