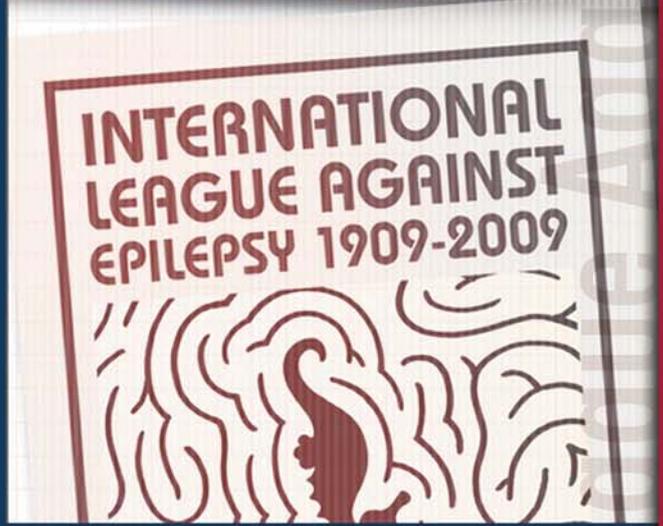
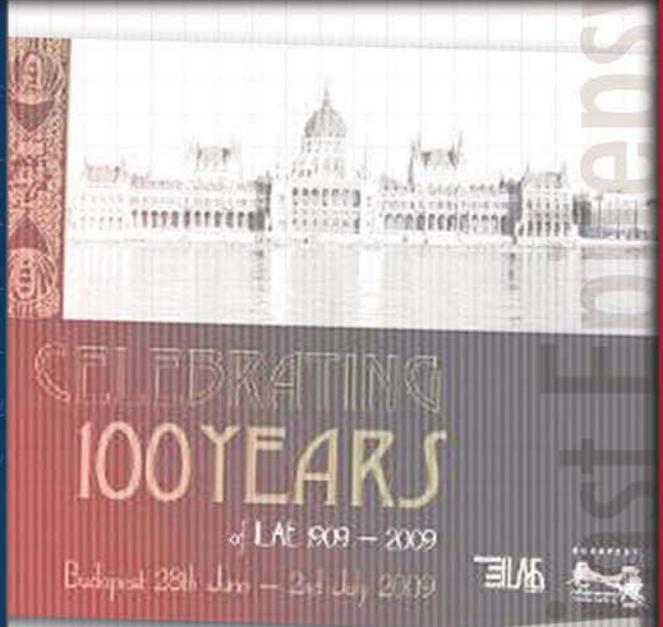
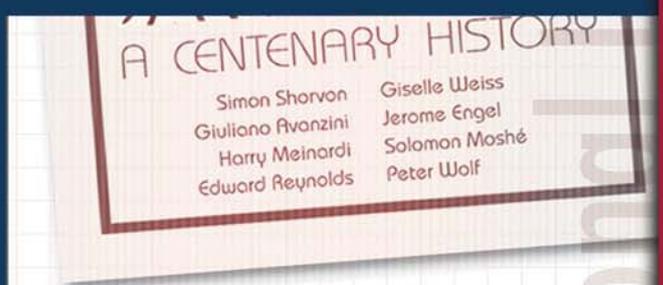


100th
Anniversary

INTERNATIONAL
LEAGUE
AGAINST
EPILEPSY **ILAE**
ESTABLISHED 1909



2008-2009 Annual Report



OUR VISION

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

OUR MISSION

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

TABLE OF CONTENTS

GOVERNANCE

Executive Committee (2005 – 2009)	2
President	3
Secretary-General	4
Chief Staff Officer	5
Treasurer	6
First Vice President	8
Vice President	9
<i>Epilepsia</i>	11
Information Officer	12
ILAE/IBE/WHO Global Campaign Against Epilepsy	14
International Director of Meetings	15

HIGHLIGHTED EVENTS

Centenary Report	17
Elections Report	19
Looking Into the Future	22

REGIONAL COMMISSIONS

Asian and Oceanian	25
Eastern Mediterranean	31
European	32
Latin American	35
North American	39

TOPIC-ORIENTED COMMISSIONS

Classification and Terminology	47
Diagnostics	49
Education	51
Epidemiology	54
Genetics of Epilepsy	56
Neurobiology	58
Neuropsychiatric Aspects	61
Pediatrics	63
Therapeutic Strategies	66

OTHER ACTIVITIES

Awards	70
--------	----

Headquarters Office

342 North Main Street
West Hartford, Connecticut, USA
06117-2507
Tel +1 860.586.7547
Fax +1 860.586.7550
Web site: www.ilae.org

Chapter Services Office

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

EXECUTIVE COMMITTEE

2005-2009

PRESIDENT

Prof Peter Wolf
Copenhagen, Denmark

SECRETARY-GENERAL

Dr Solomon L Moshé
New York, USA

TREASURER

Prof Martin J Brodie
Glasgow, Scotland

1ST VICE PRESIDENT

Prof Emilio Perucca
Pavia, Italy

2ND VICE PRESIDENT

Prof Fredrick Andermann
Montreal, Canada

VICE PRESIDENT

Dr Chong Tin Tan
Kuala Lumpur, Malaysia

***EPILEPSIA*, CO-EDITORS-IN-CHIEF**

Prof Simon D Shorvon
London, UK

Dr Philip A Schwartzkroin
California, USA

INFORMATION OFFICER

Dr Edward H Bertram III
Virginia, USA

PAST PRESIDENT

Prof Giuliano Avanzini
Milano, Italy

IBE PRESIDENT

Susanne Lund
Stockholm, Sweden

IBE SECRETARY-GENERAL

Eric Hargis
Maryland, USA

IBE TREASURER

Mike Glynn
Dublin, Ireland

PRESIDENT'S REPORT



Dear Friends,

This is my farewell message to you at the end of my four-year term as President. It was a challenging period, but also one in which important progress has been made. The League has grown further and, very appropriate for our centenary, our membership has now for the first time in history reached and surpassed the number of 100 national Chapters. With the advent of a Chapter in the world's largest country, China, the vast majority of the global population can now benefit from the activities and services of our organization. But there continues to be a potential and a necessity to grow, because the world map of the ILAE still has many blank spots, especially in Africa.

For the 2005-2009 term, we had set well-defined priorities. The first of these, the development of an educational system in epilepsy, has undoubtedly made the most visible progress, with the establishment of summer schools and other residential courses in different regions and sub-regions; with the ambitious Virepa distance education program; with programs of cooperation, exchange, and mentorship; with the establishment of a large faculty of volunteers; and with a dedicated Commission who built up a program that, if it is followed, will bring us a long way towards the aim of establishing an educational system which will be second to none in all medical specialities. The other priority, the development of epilepsy care, is closely related to the Global Campaign Against Epilepsy, our joint program with the International Bureau for Epilepsy and the World Health Organization. New initiatives have been taken, and several of these focus on Africa, where the need is greatest. Here it has also been possible to establish alliances with other organizations that are likely to improve the efficiency of our actions.

An important highlight of my period in office was the leadership meeting of the Executive with the Commission Chairs in Brussels in the fall of 2007.

Everybody who attended was excited to see the large range of activities we have developed. They provide witness to a multifaceted, highly active, and dynamic organization. Great thanks are due to all the members of our Commissions for the outstanding work they have done in these four years and the important reports and recommendations they have produced.

A centenary book has been published and will be available at the Congress in Budapest. It documents in much detail, with some half-forgotten and even some newly discovered facts, the history of our organization over its first 100 years of existence. This is the oldest existing professional and scientific society of any speciality within the neurosciences. The book proudly reminds us of the many excellent and outstanding people who have brought the League forward and made it such a successful organization. Their contributions will not be forgotten.

I wish the new leadership wisdom and awareness of the great responsibility they are being entrusted with.

I thank all of our membership around the world for their good will and for helping us improve epileptology and epilepsy care globally. I wish those of you who will attend the Budapest Congress a fruitful and a memorable centenary celebration, and I wish the rest of you the best success in your work toward our common goals.

With best regards,

Prof Peter Wolf
President



SECRETARY-GENERAL'S REPORT



During the past year, we continued activities aimed at providing outstanding educational programs and opportunities, coordinating effective translational research efforts and delivering the best epilepsy care worldwide.

One of the main responsibilities of the Secretary-General is to promote Chapter development and support their activities. At the General Assembly in Budapest on 1 July 2009 the following Chapters were officially approved: Guinea, Ghana, Mali, Palestina, Uzbekistan and Vietnam, while Burkina Faso and Congo were disaffiliated. We are currently working on applications from Bosnia Herzegovina, Cambodia, Cameroon, El Salvador, Haiti, Iran, Ivory Coast, Kuwait, Libya, Luxembourg, Mozambique, Nigeria, Oman, Puerto Rico, Rwanda, Sierra Leone, Sri Lanka, Sudan and Yemen. In the discussions involving new Chapters, we have included the Regional Commissions, as the Regional Commissions know better the particulars of the Region and may provide guidance and input to issues that may be region-specific.

The translational research document generated at the Chapter convention during the 2007 International Epilepsy Congress was circulated to the Chair of the Education Commission. The next step is for Commissions to develop a plan.

During this term, Emilio Perucca, First Vice President and I have worked on a new document describing the Constitution and Bylaws of the ILAE. This document which describes some changes in the Constitution and the Bylaws was presented at the Chapter Conventions held in Xiamen, Berlin and Montevideo. The document was also circulated to all Chapters and we received thoughtful comments. After discussion further revisions were recommended. A Task Force has been formed to draft revisions and the project will continue into the next term.

Another project this term was to draft a Conflict of Interest policy. The document was finalized by the current Commission Chairs and will be sent on to the new Chairs (2009-2013) for review and ratification.

A committee worked on the guidelines of neonatal seizures and guidelines of epilepsy in infancy that was sponsored by the World Health Organization, the International League Against Epilepsy, OASI Institute for Research and Mental Retardation and Brain Aging, the WHO Collaborating Center for Training and Research in Neuroscience, and the IBE. A comprehensive review of the literature took place and a meeting was held in Troina in March of 2009. We expect publication later in the year.

The Commission Chairs drafted a document describing rules and guidelines regarding the commission meetings. This document will be sent to the new Chairs (2009-2013). Overall, the commissions have been working very closely and are developing common projects that enhance the missions of the League.

The International AED Database on the ILAE Web site needs to be updated. Information was solicited at the Chapter conventions held in Berlin and Montevideo. Reminders to maintain the online information are sent regularly via the *Epigraph*. Better ways to keep the information up-to-date will be discussed.

As my term comes to an end, I want to thank the staff in the Executive Office: Peter Berry, Donna Cunard and Cheryl-Ann Tubby as well as Sofie Peters and Nele Devolder in the Brussels office. I greatly appreciate all their efforts.

Solomon L Moshé, MD
Secretary-General

CHIEF STAFF OFFICER'S REPORT



The past year has been a busy one, and a year of transition.

From a staff perspective, the following ten projects stand out as accomplishments over the past twelve months:

- Assisted with the League's Centenary Celebration. The marketing and fulfillment of the commemorative book as well as coordination of various activities that took place in Budapest during the International Epilepsy Congress.
- Worked with the Elections Committee on the selection of a new Executive Committee for the 2009-2013 term.
- Coordinated meetings of the International Chapter Convention and General Assembly at the IEC in Budapest.
- Assisted with the logistics and details associated with the development of the new Strategic Plan.
- Worked with the Commission Chairs in assisting them develop their plans and budgets for the next term. Staffed two meetings – one outside Paris in October and the other in Boston during the December AES Meeting.
- Coordinated the development of a new long term agreement with Wiley-Blackwell for the publishing of Epilepsia.
- Managed the transition of the move of the Chapter Services Office from Brussels, Belgium to Dublin, Ireland.
- Prepared a Commission Operations Manual for use by the 2009-2013 Commission Chairs.
- Implemented a new database software program that will allow the League's volunteer leaders and Chapter members to access and maintain their contact information in real time.
- Began the implementation of a new on-line communication tool that will facilitate communication for the Commissions. Also included in the software package will be an eGroup module that will allow groups to discuss topics and a Resource Library for posting topic based resources.

Early in 2009, the League's Officers encouraged the consolidation of the Brussels Office with the International Director of Meetings (IDM) Office in Dublin, Ireland. We thanked Nele Devolder and Sofie Peeters for their dedicated service to the League. The Brussels Office was created in 2001 and greatly assisted the League with communications, especially relating to the Chapters.

Gus Egan and Carla Glynn were designated by Richard Holmes to work with the League to support the Chapters. Gus has been with the IDM Office since 2005 and has 16 years of event management experience in the corporate



and non-profit sectors. He holds a degree in International Marketing and Japanese from Dublin City University.

Carla Glynn joined the IDM Office in 2007. Carla has over 25 years of experience in administration, communications, marketing, and corporate event management. She specializes in systems, procedures, and information technology. Carla holds a degree in Business Administration, and information technology training.



Historically, minimal staff support was budgeted to provide day-to-day coordination of the League's Commissions. 2009 saw the appointment of Emily Fournier to work with the Commissions. Emily is based in the Hartford Office and has strong staff competencies with meetings and communications. Emily's work in support of the Commissions will center around the following areas: 1) Provide meeting planning services for Commission Meetings, Work Groups, and small symposiums sponsored by the Commissions; and 2) Oversee and manage the communication mechanisms that are being implemented to enhance communication between Commissions and appropriate sub-commissions.

Emily holds a Bachelor of Science degree from the University of Connecticut where she majored in Marketing and minored in English. Emily held previous positions with the Massachusetts Bar Association and Raceway Media.



My sincere thanks to Donna Cunard and Cheryl-Ann Tubby for their hard work on behalf of the League this past year. Donna serves as the League's Financial Manager and works closely with the Treasurer. Donna oversees all of ILAE's financial transactions and the production of the monthly financial statements. She also liaises with the League's accountant on the preparation of the annual tax return and Audit Report.



Cheryl-Ann Tubby is the primary staff contact for the League's Information Officer. In addition to her Web site management responsibilities, Cheryl-Ann also coordinates the production and distribution of the League's newsletter, Epigraph, and the Annual Report.



Staff looks forward to 2010 and will build upon past efforts in support of the ILAE's Executive Committee, Commissions, and Chapters.

Peter J Berry, CAE
Chief Staff Officer

TREASURER'S REPORT



We will all remember 2008 for the sudden, if not totally unexpected, global economic crisis that had such a great impact on our personal and business finances. Unfortunately, the League was not immune to this financial downturn. This is in spite of our relatively conservative investment policy with a portfolio consisting of approximately two-thirds cash and fixed income investments, such as bonds, certificates of deposit and treasury notes. By the end of 2008, the League's investments had declined in market value by approximately 20%.

The League's earnings for 2008 were, however, quite strong (Exhibit A). The largest source was from the Regional Congresses, the majority coming from the 8th European Congress on Epileptology held in Berlin, Germany and jointly hosted by our German and Israeli Chapters. Other Regional Congresses held in 2008 were the 7th Asian and Oceanian Epilepsy Congress in

Xiamen, China and the 5th Latin American Congress in Montevideo, Uruguay. The approximate \$1 million in publication revenue came primarily from *Epilepsia* royalties.

Congresses and unrealized investment losses accounted for the majority of the League's 2008 expenses (Exhibit B). The Commissions, charged with the task of translating the League's global mission into action, accounted for the next largest expense category followed by administration, governance and special projects. Including the unrealized investment losses, the League experienced a deficit at the end of 2008 of approximately \$1.46 million. Without these we would have ended the year with a small surplus.

(continued on page 7)

2008 FINANCIALS

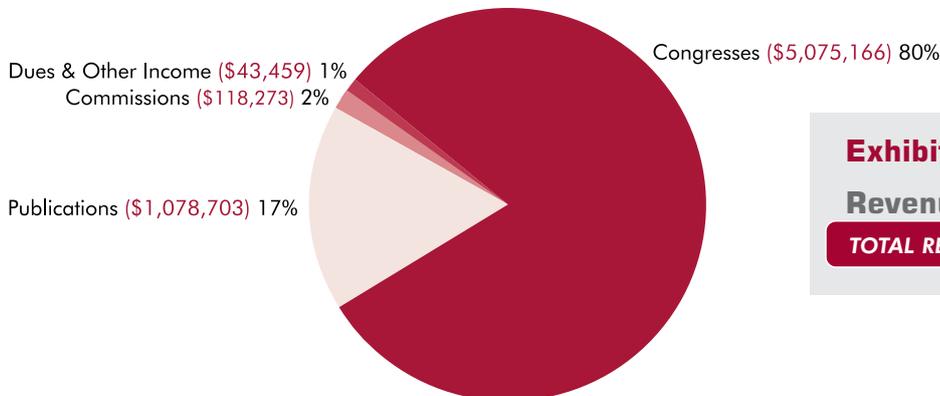
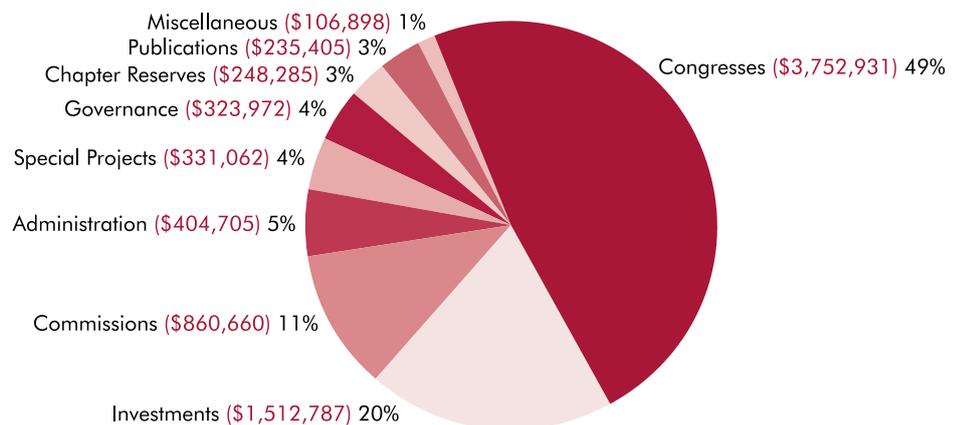


Exhibit A: Revenue

TOTAL REVENUE \$6,315,601

Exhibit B: Expenditure

TOTAL EXPENDITURE \$7,776,705



TREASURER'S REPORT (continued)

At the start of my term as Treasurer, the League adopted a spending policy to promote two important initiatives. The first was to underwrite regional development by assisting newer Regional Commissions with their agendas and programs. Secondly, 3% of our investment portfolio was dedicated annually to new projects. I am happy to report that we were able to accomplish these initiatives by drawing upon strong earnings from previous years (Exhibit C). Over the past four years, the League successfully promoted a variety of educational efforts and other programs globally while preserving the core of its financial reserves.

Unfortunately, however, spending will be more restrictive in the near future. Less robust investment earnings in conjunction with other threats to our revenue sources, specifically open-access publishing and declining pharmaceutical support, will force the League to prioritize more, thus requiring us to make

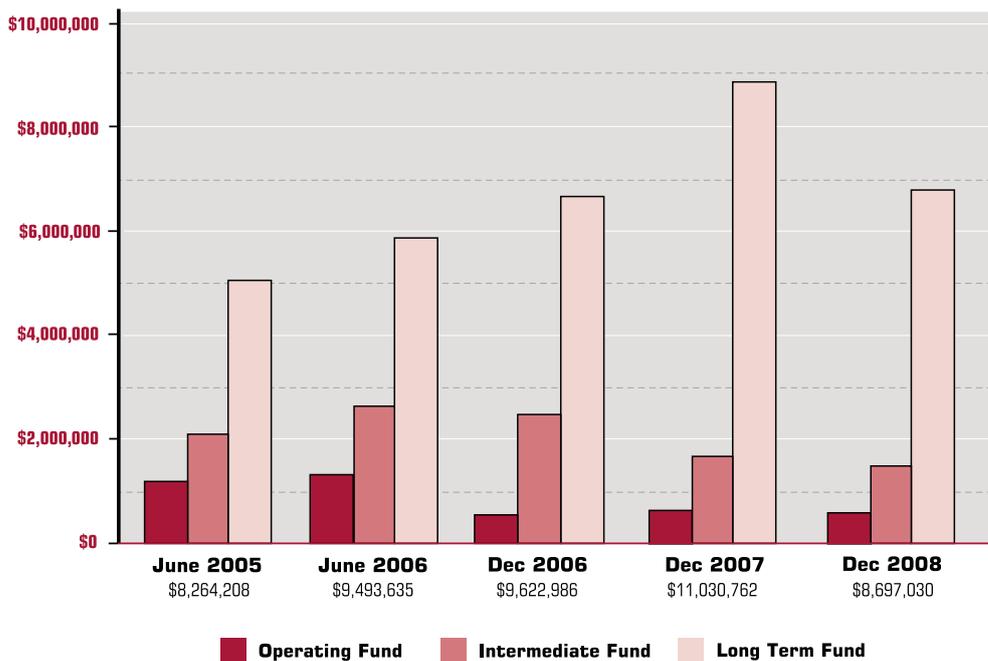
difficult decisions about future projects and initiatives. Predictions for continuing global financial instability and uncertainty present a challenge to all of us whether as individuals or volunteers committed to understanding and treating seizures. Despite these financial concerns, the work of the League will continue to make a major difference to the lives of people with epilepsy around the world.

Respectfully submitted,
 Martin J Brodie
Treasurer

INVESTMENT PORTFOLIO

Exhibit C:

June 25 - December 2008



NOTE: In 2006, the League's fiscal year end was changed from June 30th to December 31st. The December 2006 figures above represent a 6-month "short" year to adjust for the new accounting period.

REPORT OF ACTIVITIES — FIRST VICE PRESIDENT



My activities during the last 12 months can be summarized as follows:

Finalization of proposals for the revision of the ILAE Constitution. Through a fertile collaboration with the Secretary-General and other members of the Executive Committee, a draft has been finalized for a number of changes to the ILAE Constitution. One of the most significant changes is the proposed representation of each region in future Executive Committees. A decision has been made to continue discussion with the constituency about these proposals, and to submit the final version for approval at the General Assembly in 2011, in order to allow implementation in time for the election of the next Executive Committee.

Collaboration with the work of Task Forces and Commissions. This includes, in particular, my contribution to the activities of the Commission on Education and the Commission on Therapeutic Strategies, and participation in the production of the final document of the Task Force for Definition of Refractory Epilepsy. I am currently involved in further work with the joint ILAE-AAN Task Force for the production of guidelines on AED use in HIV-infected patients.

Faculty of 1000. The Faculty Database is now publicly accessible in the ILAE Web site. New additions are being regularly made, and provisions have been put in place to allow continuous updates.

African activities. The main focus of African activities has been the definition of a six-year program to improve the lives of people with epilepsy in Ghana, to be carried out in two phases in collaboration with the Ghana's ILAE Chapter, Ghana Health Services and BasicNeeds, a British NGO. The first stage focuses on the training of healthcare workers on a national scale. This program is already underway, with the organization of interactive courses targeting motivated physicians and nurses from all regions of Ghana, with facilitated participation from personnel working in Northern, Upper West, Upper East and Greater Accra Regions. The courses use a train-the-trainer model, whereby attendees are expected to be involved in directing the training of other health personnel in their geographical area. The first events took place in early August 2009 and included an intensive course for general practitioners in Accra and a course for community psychiatric nurses and assistant medical officers in Tamale. The main purposes are to make health personnel more aware of diagnostic issues, to give them greater skills in communicating to patients and families what epilepsy is and how it should be treated, as well as to provide them with improved abilities in choosing and using medications and in keeping records of people under their care. The courses are also expected to pave the way for a

demonstration project in the country. The Faculty of the first two courses included Albert Akpalu, Giuliano Avanzini, Henry Fraimow, Jackie French, Nico Moshé, Sammy Ohene, Ley Sander, Vivian Suarez, Peter Yaro and me. Funding for the first phase of the project was secured through direct support from ILAE and BasicNeeds and educational grants provided by a group of pharmaceutical industries (Pfizer, Sanofi-Aventis and UCB). Local health authorities were extremely supportive and were involved in the selection of participants, in providing allowances to course attendees and in assisting with logistics and infrastructure.

The second stage will involve further training events at regional and sub-regional levels, to provide knowledge and skills to health personnel who did not take part in the initial courses, and to target specific programs to groups of community workers and traditional healers. In parallel, an epidemiological study will be conducted to determine the prevalence of epilepsy in representative districts as well as the size of the treatment gap, and to establish programs to improve access to care and social support services. Follow-up surveys are envisaged after three and six years to determine the impact of these initiatives.

Epilepsy and sports. Initiatives are underway to utilize sport events as a means of communicating key messages about epilepsy and the scope of ILAE activities to the public. The first of these initiatives was accomplished with the help of the current ILAE President, the ILAE Commission on European Affairs (Michel Baulac), Swedish Chapter members (Elinor Ben Menachem and Torbjorn Tomson) and the French Chapter (Alexis Arzimanoglou and Hervé Vespignani) as well as support from IBE. The initiative was the establishment of a partnership with the European Football Federation (UEFA) for the organization of a football event in conjunction with the Under-21 European Football Championship in Sweden. The event, which was highly successful, consisted of two short football matches played by teams of athletes with epilepsy from all over Europe, just before the kickoff of the Championship semi-finals on 26 June 2009. The teams also included some top-level former professional football players, who generously agreed to come to Göteborg and Helsingborg to support our cause. The purpose of this initiative, which was associated with the production and dissemination of educational material through the media, was to improve public knowledge about epilepsy and to emphasize that persons with epilepsy are entitled and able to live a normal life and to engage fully in social and professional activities, including sports.

Emilio Perucca
First Vice President

VICE PRESIDENT'S REPORT



My main responsibilities as Vice President were to provide a link between the Asian & Oceanian Region and the central leadership for feedback from the region to the Executive Committee (EC), as well as oversee the development of the Region. Following is a brief summary of the development of the Region, and some comments for the future.

Congresses: Asian & Oceanian Epilepsy Congress (AOEC)

Two AOECs were held during the 2005-2009 term; the 6th in Kuala Lumpur, and 7th in Xiamen, China. Since the 5th AOEC in Bangkok in 2003, these Congresses have become a truly Asian Regional Congress with a large number of delegates from countries across Asia. The AOEC is now a stable feature of epilepsy activities in the Asian & Oceanian Region. The Congress attendance now approaches 2,000. There is also a small financial profit.

The preparations for the 8th AOEC in Melbourne in 2010 continue to progress well. It is expected that the Melbourne Congress will be another milestone of progress for the Region, in particular the strong scientific program. The location for the 9th AOEC is currently under discussion. My personal preference is Bali in Indonesia. The reasons are mainly that Indonesia has a large population (220 million) and the Congress can make a meaningful impact to fulfill the mission of ILAE. Also two previous international Congresses were pulled out of Bali (to Buenos Aires and Kuala Lumpur), and Bali is a popular destination with adequate facilities.

Education: Asian Epilepsy Academy (ASEPA)

The educational activities through the Academy are mainly in four areas: teaching workshops, EEG certification examination, fellowships, and publication of AOEC proceedings.

Teaching Workshops

Each year, about a dozen workshops of about ten different themes were conducted with total attendance of approximately 1,400. The teaching workshops are an important means to train the new generation of epileptologists in Asia. It is also a practical way for the ILAE to empower, and connect with the local Chapters. In my view, the impact and importance of these workshops is different but equal to that of the Regional Congresses, and much more cost-effective. Hopefully the program will continue to grow. Finance continues to be a limiting factor. The yearly total budget for the workshops is about USD \$100,000. ILAE's contribution through ASEPA is about USD \$20,000. Drs Seino, Yagi and Inoue raised about USD \$30,000 yearly from the Japan pharmaceutical companies. The rest was raised from other sources.

EEG Certification

Dr S H Lim is the main person driving the EEG certification examination, which consists of two parts. Part I consists of MCQs, and Part II is the practical. To date 90 candidates have taken the Part I examination with a 60% passing rate, and 21 have taken the Part II examination. The Part II examination in particular, is human resource intensive. However, it is clear that the EEG certification examination is a very effective way of improving the EEG reading skill in the Region, demonstrated by the situation in Indonesia. Its acceptance in China will be the next breakthrough. The ILAE does not contribute financially to the certification, other than indirectly by financing some of the speakers for the teaching workshops where the examinations are being held.

Fellowship

Each year, six to seven fellowships of six to twelve months duration are being offered by the Epilepsy Research Foundation of Japan, Japan Epilepsy Society, Epilepsy Society of Australia and ASEPA. It is an important element in the nurturing of future epilepsy leaders in the Region. The ILAE's direct financial contribution through ASEPA is USD \$10-12,000 per year for two fellowships.

Proceedings of AOEC

A proceeding of the Kuala Lumpur AOEC was published as a supplement of *Neurology Asia*. There was a delay in the publication of the Xiamen AOEC proceeding. The proceeding helps to enhance the educational/scientific value of the Congresses. The financial cost is about USD \$5,000 for each proceeding.

Epilepsy Care

There are three Global Campaign type demonstration projects in the Asian & Oceanian Region, where members of the ILAE are involved; China, East Timor and Laos. The East Timor project is mainly by the Epilepsy Society of Australia. ILAE's role for the Laos project is mainly in education. The financial cost is about USD \$30,000 raised through the Taiwan and Japan Epilepsy Society. Hopefully the European Commission will also contribute. ILAE's direct contribution to this project is USD \$5,000.

Research

This is headed by Dr Patrick Kwan. The main project was to identify the epilepsy research priorities in Asia.

Organizational Issues Chapter Development

There were two additional members in the last four years, New Zealand and Vietnam, making a total of 18 ILAE Chapters in the Asian & Oceanian region.

(continued on page 10)

VICE PRESIDENT'S REPORT *(continued)*

Sri Lanka and Cambodia already have their national epilepsy societies, but the societies are yet to be registered by their respective government authorities. It is expected that they will join the ILAE as Chapters in the next four years. Myanmar (50 million population), North Korea (22 m), Laos (6 m), Papua New Guinea (6 m), Fiji (0.8 m) and East Timor (0.8 m) are the other countries in the Region without an ILAE Chapter. With further efforts, it is possible that Myanmar and Lao will also be able to form national epilepsy associations and thus ILAE Chapters.

Presently 97% of the Asian & Oceanian population is represented by ILAE Chapters, which is an enormous growth over the last decade. The next goal is for these Chapters to be fully functional. Most ILAE Chapters in the Region are reasonably active. However, only a few can be said to be fully functional. It is the role of the future ILAE central and regional leadership to help empower and nurture the Chapters toward further growth. The ASEPA workshops, usually with the national Chapters as local organizers, are important means for the ILAE to help these Chapters in a practical way. It is a pity that due to various reasons, the ASEPA had to turn down the requests by Bangladesh, Sri Lanka and Nepal national associations to organize workshops in their respective countries during 2009.

Leadership Transition

Dr M Seino, who has done so much to contribute to the development of ILAE in the Region, passed away in April 2007.

Future Challenges

There is tremendous economic growth in many countries in Asia, such as China, India, Vietnam and Indonesia. This will be translated to growth in medical care resources including epilepsy. It augurs well for the future development of epilepsy in the region.

As mentioned above, about 97% of the population in the Asian & Oceanian Region is now covered by ILAE chapters. An important challenge for the immediate future is how the ILAE through the regional network or centrally can help the Chapters develop fully, and thus fulfill the mission of ILAE.

I see the cohesiveness of the Asian & Oceanian Region as a body to be another big challenge for the future. This is a region sharing only a common geography, but with very diverse language, culture, religion, socio-economic status, and sophistication in epilepsy care. There are also historical animosities among many of

the countries. The effective functioning of the Region is dependent on the key national leaders from different backgrounds being able to work together. Long term, working together despite diverse cultures will be enhanced if there is a strong "Asian epilepsy community spirit," which may require conscious nurturing.

It is also important that the Region has strong links with the Executive Committee. As the Region is represented in the Executive Committee through the Vice President, how its Vice President should be elected is an important issue that should be addressed in the coming term.

Chong Tin Tan
Vice President

EPILEPSIA REPORT



Epilepsia had a successful year in 2008 with 495 papers published and indexed (including supplement articles). This is an increase of 12% compared to the previous year. The Journal had a record number of over 900 full submissions with additional contributions to the Gray Matters section. Papers were accepted from all continents and the Journal now has truly global coverage. Because of lack of space and the increasing number of submissions, the Journal has had to turn down over 70% of the papers submitted. Each of the 12 issues had a particular theme, which included: clinical science (January), basic science (February), drug therapy (March), global epilepsy (April), imaging (May), clinical epilepsy (June), pharmacology (July), epilepsy surgery (August), pediatric epilepsy (September), experimental physiology (October), epilepsy syndromes (November) and clinical semiology (December). The total income received from the publisher by the ILAE was \$900,000. A total of 2,453 editorial pages were published in 2008 including the following supplements:

Supplement 1 – The Management of a First Seizure

Supplement 2 – Early Glial Dysfunction in Epilepsy

Supplement 3 – Mapping Epileptic Circuitry (AES Merritt-Putman Symposium)

Supplement 5 – Persistent Hippocampal Neurogenesis

Supplement 6 – Central Nervous System Infections and Epilepsy

Supplement 7 – Abstracts 2008 Annual Meeting of the AES (online only)

Supplement 8 – Ketogenic Diet and Related Dietary Treatments

Supplement 9 – Decision Points in Epilepsy: Bedside to Bench (AES Annual Course)

(Supplement 4 was an author and subject index for the 2007 year which was inadvertently omitted by Wiley-Blackwell)

The second Morris-Coole Prize was awarded at the ILAE European Epileptology Congress to Nicola Marchi, an Italian postdoctoral fellow working in the laboratory of Professor Janigro in Cleveland, for his paper: Marchi N et al. Seizure-promoting effect of blood-brain barrier disruption. *Epilepsia*. 2007 48:732-42.

At the end of 2008, there were 750 institutional subscriptions, and there was a 9% increase in the number of institutions that opted for online subscription. In addition, over 3,980 libraries globally had access to *Epilepsia* through the consortia sales program. There were also 1,939 individual member subscriptions. *Epilepsia* articles were downloaded 678,846 times during 2008 via the Wiley-Blackwell Intersciences Platform, an increase of 6% compared to the previous year. In addition, there were 190,403 PubMed linkouts to *Epilepsia* articles, an increase in 84% compared to 2007.

The team of associate editors continues to give superb service to the Journal. Through the year, the associated editors were: Ettore Beghi, Edward Bertram, Amy Brooks-Kayal, Mark Cook, Michael Duchowney, Renzo Guerrini, Bruce Hermann, Philip Patsalos, Michael Sperling, Annamaria Vezzani and Matthew Walker. Anne Berg stood down in October 2008, and her place was taken by Torbjörn Tomson. The Editorial Board at the end of 2008 was comprised of 51 persons from 20 countries and these peer reviewers have provided unrivalled expertise to the Journal. The smooth functioning of *Epilepsia* continues to rest in the very capable hands of our Managing Editor, Alison Alsmeyer who works closely with our excellent Production Editor at Wiley-Blackwell, Cathy Krendel. We are also happy to acknowledge the exceptional contributions of the editorial assistants, Elizabeth Mobayed and Laurie Beninsig. Alison Labbate, Publisher, and her editorial staff at Wiley-Blackwell have continued to provide a high level of expertise and support.

Epilepsia is dedicated to the general goal of advancing epilepsy research. Our ability to achieve that goal depends primarily on the authors who contribute their outstanding work to this Journal. We hope that the high quality, large distribution, and epilepsy-focused readership of *Epilepsia* will continue to make this journal a primary target for the best in epilepsy research.

Simon Shorvon and Phil Schwartzkroin
Joint Editors-in-Chief Epilepsia

INFORMATION OFFICER'S REPORT



The information officer of the International League Against Epilepsy has several defined responsibilities and a number of ad hoc assignments. The primary responsibilities include the oversight of the web site and the editing and publishing of Epigraph, the League's newsletter.

ILAE Web site: The ILAE Web site was initiated in 2000, and the Information Officer is responsible for its content and development. The technical management of the Web site is run by the ILAE office in Hartford, and the Hartford staff member serving as a link between the executive committee and the programming staff is Cheryl-Ann Tubby. She is also the primary contact point when questions and requests come from members or outside organizations or individuals.

The Web site serves a number of purposes: repository of information regarding the League's organization and function, basic information regarding national chapters (officers, contacts, Web site chapter URL's), commission reports, links to meeting web pages, access to educational material (including the latest revisions to the classification system) and archives of current and past publications. One resource on the Web site that members find useful is the database of the names of antiepileptic drugs used around the world. Originally designed and created by Dr. Robert Fisher, this database has proved useful in this era of widespread international travel in which physicians are encountering patients who are taking medicines that have different names in different countries. The database allows a physician or patient to convert names across countries. This service requires ongoing updates and is dependent on information provided by all of the chapters. As keeping the information up to date requires much effort on the part of chapters and staff, we are seeking other means which are less burdensome of keeping data current.

Another feature that is very popular is the Epilepsy Bibliography, which is a regularly updated compendium of all available publications dealing with epilepsy in all languages. This resource is provided through the considerable and ongoing efforts of Prof. Yukio Fukuyama. At the moment the updated information comes to us as completely redone data that has to be reloaded. In addition to being labor intensive, this process means that the information is out of date for longer periods of time. To overcome both problems we are working with Prof. Fukuyama to create a direct data entry system so that all new information is entered as it becomes available in a standard format. Over half the visits to the League's website are to the bibliography and the international antiepileptic drug database.

Two features that were added to the League's website are the Bookstore and the Farewells sections. The first is an area of the Web site in which we place information on books that are epilepsy related so that members will know what is available. The League does

not sell the books, but links to booksellers are provided. We contacted a number of publishers as well as authors of epilepsy books, and introductory offers of gratis placement (the plan has been to make a small charge for the service) were made. To date the response has been minimal, and only a small number of books have been placed. In the coming year we will make another effort to expand the number of books placed on this site, but if the response remains weak, we will consider discontinuing the service.

The Farewells section contains the obituaries of past members and others who were involved in the epilepsy movement across the globe. The intent of this section is to inform the larger epilepsy community about the passing of colleagues, to celebrate their accomplishments in moving epilepsy care forward, and to create an historical archive of people who have helped improve the lives of patients with epilepsy. Although we may solicit obituaries from time to time, we will also depend heavily on our international membership to inform us about the lives and accomplishments of our departed colleagues. In the last year there were several notable deaths that were added to the list. In addition we received from Harry Meinardi, former League president, files of all the obituaries that had been published in *Epilepsia*. This glimpse into the history of the ILAE through the lives of many leaders of the field is available in the archives section of Farewells.

Over the years, the Web site has grown and has attracted increasing traffic and there were almost 800,000 visits in the past year. The Web site is a key public face for the League, in which its goals and programs are presented. As the goals of the League and the needs of its members change the Web site will also change. In the past year we have been making simple changes to the organization of the sections, primarily to make some parts more obvious and accessible. There have been a few cosmetic changes to reflect the international nature of the League and to remove clutter from several of the initial pages. The most substantive changes took place in the classification section. Although the Commission on Classification and Terminology has been working steadily, the Web site was not up-to-date and did not reflect the League's current position. With the leadership of Dr. Anne Berg, the Commission's chair, the classification section was revamped. Links to appropriate descriptions of syndromes were provided, and we placed a number of key papers over the last 40 years that concern the classification, so that visitors can make easy use of source material. In the coming year we expect further changes and additions of new material to make this section more attractive and useful.

Epigraph: The newsletter of the ILAE was launched in 1994, and was intended from its inception to provide

(continued on page 13)

INFORMATION OFFICER'S REPORT *(continued)*

short summaries of ILAE activities and include occasional features of general interest to an epilepsy audience. Most importantly it is a means by which the ILAE central office could communicate with members worldwide important events. Since 2006, *Epigraph* has produced four issues a year (three on-line and one print edition). In 2009, the centenary year for the League the paper issue was provided at the International Congress in Budapest. Among other topics, this issue introduced the new Executive of the League, which had been elected in a series of elections earlier in the year.

Issues for the Immediate Future

The nature of the League continues to evolve in scope and in goals, as the membership spreads to more countries and regions, the chapters strengthen and the interaction within the international epilepsy community grows. Although many of the interactions are based on personal contacts, collaborations can be started or enhanced if communication is improved. One of the biggest hindrances to informing individuals about League activities and opportunities for collaboration or development is the inability of the League to communicate with the larger membership. This problem has arisen because of incomplete listings of members of the individual chapters and the lack of email addresses for many names that we do have. Although there are some valid reasons why this information has been difficult to achieve (largely privacy concerns), the ability to communicate with the worldwide epilepsy community is a critical component

of a professional society that wishes to move its agenda forward. In the coming year developing a comprehensive database of members names will be a major goal.

Communication within the League is not as easy or efficient as it should be in this age of universal electronic communications. The League has not developed the infrastructure or the culture of regular interactions among commission and task force members, and this deficit clearly is a hindrance to progress on the many issues that the League wishes to address. To help achieve our many goals, we are in the process of providing improved on-line services to our commission members that will allow for simpler access to project materials and more regular and efficient meetings through Web conferencing.

A major issue that is facing the epilepsy community is the lack of recognition and support that epilepsy receives in relation to the impact of the disorder on the individual and society. The many epilepsy groups are now coming together to improve the situation through greater public awareness of the problem. In the coming year we will be developing a program that will target groups and individuals that are in positions to influence the allocation of resources so that epilepsy receives the support that befits the seriousness of the condition.

Edward H Bertram III
Information Officer

ILAE/IBE/WHO GLOBAL CAMPAIGN AGAINST EPILEPSY (GCAE)



Since its inception in 1997 the GCAE strategies and activities have been designed according to the Global Campaign mission statement: "To improve the acceptability, treatment, services and prevention of epilepsy worldwide."

The two NGOs, ILAE and IBE are in official relations with WHO and over the years have contributed to a number of departmental activities in the area of neurology including the production of the report "Neurological Disorders: Public Health Challenges."

Global Campaign Activities To Date Regional Conferences

Regional Conferences were organized in all six WHO Regions between 2001-2004

Regional Declarations on Epilepsy

As part and as a result of the Regional Conferences, Regional Declarations on Epilepsy have been developed and were unanimously agreed upon in all Regions.

Regional Reports on Epilepsy

Regional reports provide basic knowledge on epilepsy and facts about the epidemiological burden in the Region, as well as proposing the next steps to be taken. Reports have been published in: AFRO, AMRO (Spanish version), SEARO and WPRO. The reports for the European and EMRO Regions will be published shortly.

Development of Professional and Lay Organizations

One of the activities of the Campaign has been aiming at assisting IBE and ILAE to extend their memberships.

Demonstration Projects

Demonstration Projects have been developed, implemented and completed in: China, Brazil, Zimbabwe and Senegal. A project is ongoing in Georgia and another one has been initiated in Cameroon. A number of projects have been developed in SEARO by the WHO Regional Office.

Atlas Project

Within the WHO Atlas Project an Atlas: Epilepsy Care in The World was developed and published in 2005.

Project on Stigma

Within the Campaign, a grant for a pilot project on stigma in epilepsy was obtained from the Fogarty Foundation (National Institutes of Health, USA) in collaboration with the University of Liverpool, United Kingdom. This project led to four publications in *The Lancet* and *Epilepsy and Behavior*.

Project on the Burden of Epilepsy

Information on epidemiology of epilepsy worldwide has been collected to calculate the burden of epilepsy. This would be an important contributor to the initiative Global Burden of Disease 2005 which aims to produce comprehensive and comparable estimates of the burden of diseases, injuries and risk factors for two time periods, 1990 and 2005.

Development of Guidelines for the Treatment of Epilepsy in Children and Adolescents

Guidelines for the treatment of epilepsy in childhood and adolescence are being drawn up in collaboration with the WHO Department of Child and Adolescent Health and Development. Evidence-based guidelines for management of neonatal seizures in resource poor settings was the first initiative.

Project on Legislation

Within the framework of the ILAE/IBE/WHO Global Campaign Against Epilepsy a project on "epilepsy and legislation" has been performed. Two documents were developed: "Guidance instrument for developing, adopting and implementing epilepsy legislation" and "Basic principles for epilepsy legislation" and are now almost ready to be published.

Results of Global Campaign Activities on a National Level

- Since 1997, 135 IBE/ILAE organizations in 103 different countries have been actively engaged in hundreds of Global Campaign-related activities, covering 5.5 billion of a world population of 6.4 billion (86%).
- In a recently conducted survey on Global Campaign activities in countries, two-thirds of Campaign activities were reported by the organizations to be either very successful or moderately successful. Thirty-nine percent reported it to be very successful.
- Ninety percent of those surveyed said they would continue to be active in the Global Campaign in the future.

Hanneke de Boer
Coordinator for the Secretariat of the Global Campaign Against Epilepsy

INTERNATIONAL DIRECTOR OF MEETINGS REPORT



Annual Congress Planning Update

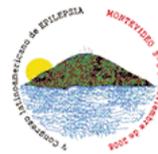
During the year July 2008 to June 2009, the IDM Office has been actively engaged with the management and operation of the Congresses which took place during this period, in addition to the planning for future meetings.

During this time, the IDM Office has seen the successful organization of the 8th European Congress on Epileptology, which was held in Berlin in September 2008, the 11th European Conference on Epilepsy and Society, which was held in Marseille in October 2008, the 5th Latin American Congress on Epilepsy, which was held in Montevideo in November 2008 and the 28th International Epilepsy Congress, which took place in Budapest in June/July 2009. Work is underway on the international and regional Congresses for 2010, 2011 and 2012.



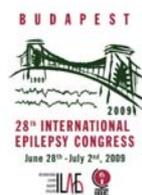
The 8th European Congress on Epileptology (ECE), jointly hosted by the German and Israeli Chapter of ILAE, was held in Berlin from 21 to 25 September 2008. The Congress, which took place at the Berlin International Congress Centre, was

a great success and attracted 3,733 delegates from all over the world (461 delegates from outside Europe). The IDM Office worked in close collaboration with Meir Bialer, Christian Elger and Ruediger Koehling, coordinating the scientific program, the on-site logistics and sponsorship and exhibition contracts. The four main topics which had been selected by the ILAE Commission on European Affairs were "Immune processes in epilepsy: basic and clinical issues," "Pharmacogenetics and pharmaco-genomics in epilepsy," "Predicting the response to AEDs" and "Synaptopathies in epilepsy." Teaching sessions and a "How to Do" course took place each morning, under the academic umbrella of EUREPA. The most popular session in Berlin was the Chair's Symposium, which was entitled "Epilepsy as a disease and as a model" (with more than 1,000 attendees). It is also important to note that Platform Sessions were exceptionally well-attended with an average of 300 delegates per session. Over 750 abstracts were submitted via the online system. Poster presenters were given the option to submit an e-poster instead of a traditional poster. The German Academy Day, organized by the German Chapter of ILAE, took place the day before the Congress officially commenced. The European Epileptology Award 2008 was jointly awarded to Simon Shorvon (UK) and Uwe Heinemann (Germany) and a Special Recognition Award was given to Dieter Janz (Germany) for his contributions to the field of Epileptology.



The 5th Latin American Congress on Epilepsy (LACE) took place at the Radisson Victoria Plaza Hotel in Uruguay, from 5 to 8 November 2008, attracting 656 participants, which was the highest number of delegates to date for a Latin American Congress on

Epilepsy. This was an increase of 54 percent over the 4th LACE in 2006. The main themes of the Congress were "Neuroimaging," "Epilepsy Surgery and Etiologies," "Epilepsy Cognition," "Controversies in Pediatric Epilepsies," "Morbi-mortality and Epilepsy" and "Basic Research in Human Tissue." There were a total of 25 sessions including a Presidential Symposium, six main sessions, five special symposia, one satellite symposium, three Platform Sessions, three discussion group sessions, five ALADE (Academia Latinoamericana de Epilepsia) courses and a highlights session. Five well-attended ALADE courses were incorporated into the Scientific Program, two of which, Neurobiology and Epilepsy Surgery, took place on the pre-Congress day. The ILAE Chapter Convention and a Program for People with Epilepsy also took place on the pre-Congress day. The Congress finished with a Highlights Session chaired by Alejandro Scaramelli, Peter Wolf and Carlos Acevedo. A total of 160 abstracts were received via the online abstract submission system. Although the official languages of the Congress were Spanish and Portuguese, authors were requested to submit their abstracts in English as well as in Spanish or Portuguese. Twelve abstracts were presented in Platform Sessions with the remainder presented as posters.



The 28th International Epilepsy Congress (IEC) took place in Budapest from 28 June to 2 July 2009. It was attended by more than 3,412 delegates. The venue for the Congress was a new pavilion at Hungexpo Fair Centre. Session attendance was good and delegates stayed on-site to enjoy

the posters and to view the Historical Wall and ILAE Centenary Exhibition, which were designed for the occasion. The Scientific Advisory Committee was co-chaired by Susanne Lund and Peter Halasz. The main topics of the Congress were: "Autonomic Functions and Biorhythmicity," "Remission or Cure – Basic Science and Clinical Outcome," "Comprehensive Care around the World," "Family and Epilepsy," "Brain Development, Plasticity and Epilepsy," "Progress in Imaging and Epilepsy Nosology" and "Non-Specialist Management of Epilepsy." The Congress also celebrated the centenary of the founding of the ILAE, in Budapest in 1909. A private dinner celebrating the 100 years of ILAE was organized at the Hungarian Academy of Science and was attended by 120 people. A special copy of the medal from the foundation of the

(continued on page 16)

INTERNATIONAL DIRECTOR OF MEETINGS REPORT *(continued)*

ILAE was presented to each participant. A film festival and competition was also organized for the occasion and many delegates were able to enjoy showings of old and modern movies depicting epilepsy. A number of prizes were awarded during the 28th IEC: the Michael Prize, the Morris-Cooles Prize, the Lifetime Achievement Award, the Social Accomplishment Award and Ambassadors Awards. The Congress was concluded by a "Highlights Session" which gave delegates the opportunity to listen to the Chairs of the seven main topics debated during the 28th IEC.



The 2nd East Mediterranean Epilepsy Congress will take place in Dubai from 4 to 6 March 2010. The program is almost finalized and both the printed announcement and Congress Web site

(www.epilepsydubai2010.org), containing full information on the Congress, will be made available in October 2009.



The 9th European Congress on Epileptology will take place in Rhodes, Greece from 29 June to 1 July 2010. The Congress Web site is now open and the abstract and registration system will be available in October 2009.

Three organizational meetings have already taken place and the program is now almost finalized. The International Organizing Committee is co-chaired by George Kostopoulos (Greece) and Michel Baulac (CEA Chair), while the Scientific Advisory Committee is chaired by Thanos Covanis (Greece). The next meeting of the SAC is scheduled to take place the last weekend of February 2010. The main topics which have been selected are "Advances in techniques to delineate the epileptogenic zone," "AED development, selection and use relevant to gender and age," "Challenging the concept of idiopathic epilepsies" and "Predicting epileptogenesis: how far are we from reaching the goal?"



The 8th Asian & Oceanian Epilepsy Congress (AOEC) will take place in Melbourne, Australia from 21 to 24 October 2010. The venue is the Melbourne Convention &

Exhibition Center (MCEC) in the center of Melbourne which opened in July 2009. There are an abundance of hotels of varying standards within walking distance of the MCEC and plenty of restaurants and cafés too.

The Scientific Advisory Organizing Committee (and in particular its Co-chairs Simon Harvey, Shih Hui Lim and Shunglon Lai) have been working arduously to devise a most attractive scientific program with international appeal; speaker invitation letters are currently being issued. The main topics of the Congress are: "Epilepsy Surgery – Who and When?," "Outcome in Newly-diagnosed Epilepsy," "Prevention of Symptomatic Epilepsy" and "Psychological Wellbeing in Epilepsy." Changes to the program include fewer sessions in parallel (there were up to seven for the 7th AOEC, but a maximum of four for the 8th AOEC), an opportunity for a late breaking news session and more interactive workshops. A two-day program on Epilepsy and Society will run in conjunction with the Congress. The abstracts and registration system will go live at the end of October 2009; the 2nd announcement will be produced at this time, too.



The 6th Latin American Congress on Epilepsy will take place in Cartagena, Colombia, from 1 to 4 August 2010. The Scientific

Advisory and Organizing Committee, Co-chaired by Manuel Campos, Carlos Acevedo and Daniel Nariño, met during the 28th IEC in Budapest and are currently planning the scientific program. Five ALADE courses (Academia Latinoamericana de Epilepsia) will be incorporated into the program. The Congress Web site is due to go live shortly with abstract submission opening in November 2009.

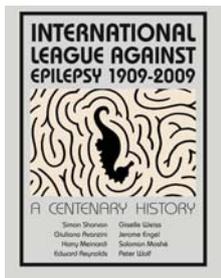
The IDM Office is also currently working on arrangements for the 29th International Epilepsy Congress, which will take place in Rome, Italy in 2011, as well as the 10th European Congress on Epileptology and other regional Congresses, which will take place in 2012.

Richard Holmes
International Director of Meetings

CENTENARY REPORT

In 2009, the International League Against Epilepsy (ILAE) celebrated its first centenary. The organization was founded on 30 August 1909 at a meeting in Budapest during the International Medical Congress of that year and to celebrate this centenary, ILAE decided to return to this city for its own 2009 International Epilepsy Congress. To reach this landmark is a remarkable achievement, and the ILAE is the oldest such international sub-specialist organization in the field of neurology, and one of the oldest in medicine. The 28th International Epilepsy Congress was held on 29 June to 2 July 2009 in Budapest, and at the Congress, several different centenary events were held:

1. Publication of *International League Against Epilepsy 1909-2009: A Centenary History*



The ILAE Executive published a centenary book with the three-fold aims of: documenting the course of the ILAE in its first 100 years, interpreting this within its historical context, and bringing together as much source material as possible. The book – *International League Against Epilepsy 1909-2009: A Centenary History* (authored by S

Shorvon, G Weiss, G Avanzini, J Engel, H Meinardi, S Moshé, E Reynolds, P Wolf) was launched at the Congress. The book is 334 pages in length and lavishly illustrated with over 100 photographs and other illustrations. Much of the material is previously unpublished, and taken from the ILAE archive and other sources. The book is published to very high production standards by Blackwell, and was made available in a limited edition of 1,000 copies, with each copy including an individually numbered bookplate. It is designed to be a collector's item and will grace the library of anyone interested in the history of their organization.

2. *Epilepsia* centenary events

This is also the centenary of the journal *Epilepsia*. The first edition was published in March 1909 (almost certainly) and *Epilepsia* was formally adopted as 'the official organ' of the ILAE in September 1909. Since then it has published many important papers in the field of epilepsy. A special issue and historical supplement were published in March 2009. The supplement contains 10 chapters covering aspects of the history of epilepsy during the 100 years. At the 28th International Epilepsy Congress, on 29 June, a special session was held which was devoted to presentations on four landmark papers in the Journal and the impact these had on the subsequent course of epilepsy.

3. ILAE Centenary historical exhibit

A poster exhibition of the 'History of the ILAE' was displayed as part of the ILAE exhibit during the Congress. This was comprised of 70 posters covering many aspects of ILAE history and the history of epilepsy, and there was also a large wall display of an historical timeline. Much of the written material for these posters was based on the centenary book and the *Epilepsia* supplement. The exhibit was entered through a historical recreation of the entrance of the 'Hotel Bristol' which is where the founding meeting of the ILAE was held. At the exit was a centenary book, inviting signatures of ILAE members to welcome the organization into its second century. The exhibit was a centerpiece of the exhibition space at the Conference, and copies of the posters and historical wall are now available on the ILAE Web site.



4. Centenary Film and Literature Festival and Film Competition

ILAE organized a Centenary Film Festival at the 28th International Epilepsy Congress. Epilepsy has featured in films for almost 100 years and continues to be a strong plot device for modern film makers. Four historical films were selected for screening as part of the ILAE centenary celebrations to showcase the history and development of the representation of epilepsy in film from the 1920s to the 21st century. The showing of each film was preceded by a brief introduction and followed by a short debate about the way epilepsy was depicted.



A Centenary Film Competition was also organized with prizes worth \$10,000 awarded for the best films made since January 2000 which were inspired by or related to epilepsy or seizures.

The competition was not for educational or clinical films, but rather for creative or artistic works which used epilepsy as a theme directly or tangentially, and the judging criterion was creative merit. The competition attracted entries from Europe, Asia, North and South America, Africa and the Middle East, representing many different film genres. These films were judged by a distinguished panel. At the Congress, the ILAE Oscar was presented to the overall winner of this competition, Gus Cummins for his short film *Ictal*, and the world premier screening of this short film was made at the Congress. The runner-up was the feature film *The Year of the Wolf*, directed by Tuomas Kantelinen. These and other entries were also shown at the Congress.

(continued on page 18)

CENTENARY REPORT *(continued)*

As part of the festival, at the 28th International Epilepsy Congress, there was also an exhibit of books, collected by Peter Wolf, which featured epilepsy as a theme, and a special session was also devoted to Epilepsy in Literature with a debate with the audience.

5. ILAE Centenary and gala dinners

A centenary dinner was held on 27 June 2009 at the Hungarian National Academy of Sciences. Invitees included previous ILAE Executive Committee members and Chairs of ILAE Commissions, and six ILAE Presidents attended. The dinner was hosted jointly with the Hungarian Chapter of the ILAE, and the Chapter presented the guests with a special medal struck to mark the centenary and based on 1909 International Medical Congress, at which the ILAE was formed.

A gala dinner celebrating the centenary of the ILAE was held in the Hungarian National Gallery for all delegates on 2 July. This is a magnificent setting and the evening was a wonderful occasion to enjoy the company of friends and colleagues, and to launch the ILAE into its next 100 years.

The centenary events were organized by the ILAE Centenary Committee which thanks the very many members of the ILAE for their kind and generous help in making the centenary so memorable.

Simon Shorvon
for the ILAE Centenary Committee



ELECTIONS REPORT

The ILAE is overseen by an Executive Committee, currently made up of 12 people. The President is elected by a ballot of national Chapters for a four-year term. The Secretary-General, Treasurer, and three Vice Presidents are also elected by a ballot of national Chapters for a four-year term. The Information Officer and the Editors-in-Chief of *Epilepsia* are appointed by the President and the Executive Committee. The Past President serves for a four-year term. There is also a Regional Representative from any active Region that is not represented by one of the officers. The President, Secretary-General and Treasurer of the sister organization, the International Bureau for Epilepsy, are Ex-Officio members of the Executive Committee.

The ILAE Executive Committee (EC) election process that started two years ago with the definition of the criteria for identifying the eligible candidates is now complete. We thank the Chapters for their enthusiastic participation in this important process. We were very pleased to see that we had such a qualified group of prominent epileptologists who were willing to serve in the ILAE EC, and we thank all of them on behalf of the ILAE. Each position on the EC is for a four-year term and the dedication of the elected volunteers is greatly appreciated by all members of the League.

The first stage of the process was completed late in 2008. From a list of three highly qualified candidates, Chapters elected Solomon (Nico) Moshé as incoming ILAE President.

In March of 2009, a list of 12 officer candidates from five Regions was circulated for the second phase of the election process. At the close of balloting, the four people with the largest number of votes fulfilled the requirement of representing at least three ILAE Regions and were duly elected. President-elect Moshé participated in the Election Committee's assignment of officer positions.

Elections for the 2009-2013 term of office have just been concluded and the new officers will assume their positions during the 28th International Epilepsy Congress.

Effective 6 May 2009, the following Officers had been placed:

Secretary-General:	Samuel Wiebe
Treasurer:	Emilio Perucca
First Vice President:	Tatsuya Tanaka
Second Vice President:	Michel Baulac

Note: The election for Vice President from the Latin American Region had not yet been completed by press time.

We warmly congratulate the elected members and wish them well for their work for the ILAE. We also would like to thank all the candidates for their willingness to participate in the elections. We hope that they will continue to contribute to the life of the ILAE.

According to the ILAE Constitution: "In the event that after the global elections...any fully operational region of the ILAE (as determined by the Executive Committee) is not present on the Executive Committee, the Chapters of this region shall elect an additional Vice President." Therefore, a supplementary election phase for an additional Vice President from Latin America was begun.

Regional Commission Chairs have been appointed for the 2009-2013 term of office. Please join me in welcoming the following to their positions:

Meir Bialer – Commission on European Affairs
Jacqueline French – North American Commission
Manuel Campos – Latin American Commission
Ahmad Beydoun – Commission on Eastern Mediterranean Affairs
Byung-In Lee – Commission on Asian and Oceanian Affairs

Giuliano Avanzini
Chair, Election Committee

Solomon (Nico) Moshé, President



Solomon L. Moshé, MD, is professor of Neurology, Neuroscience, and Pediatrics at the Einstein College of Medicine in the Bronx, New York. He is Vice Chairman of the Department of Neurology and Director of Child Neurology and Clinical

Neurophysiology. Since 1979, his research has focused on understanding the mechanisms underlying age- and sex-related differences in epilepsy in humans and animal models. In addition to his laboratory research, he is actively involved in several large multicenter studies examining the consequences of prolonged febrile seizures, absence epilepsy, and the Epilepsy Phenome-Genome Project. Over the last 20 years, Dr Moshé has mentored over 200 scientists and clinicians from around the world in clinical epilepsy and basic science epilepsy-related research.

Dr Moshé has served as President of the American Epilepsy Society (2000-2001), the American Clinical Neurophysiology Society (1996-1997), and the Eastern Association of Electroencephalographers (1992-1994). He has been a member of the Executive Committee and the Professional Advisory Board of the Epilepsy Foundation and has served as the Secretary-General of

(continued on page 20)

ELECTIONS REPORT *(continued)*

the Executive Committee of the International League Against Epilepsy from 2005-2009. He has received a number of honors and awards, including a Teacher-Investigator Development Award and a Jacob Javits Neuroscience Investigator Award from the NIH, the Michael Prize for achievement in epilepsy research, the American Epilepsy Society Research Award, the Ambassador for Epilepsy Award from the International League Against Epilepsy, the Gloor Award from the American Clinical Neurophysiology Society, and the J. E. Purkyne Honorary Medal in Biomedical Research by the Czech Academy of Sciences. He has also received the Mentor of the Year Award from his own institution and the Distinguished Service Award from the Epilepsy Foundation of Southern New York. He is an elected member of the American Neurological Association and the American Pediatric Society. He has authored or co-authored over 300 publications.

Samuel Wiebe, Secretary-General



Dr Wiebe is Professor and Head, Division of Neurology in the Department of Clinical Neurosciences at the University of Calgary, Canada, Director of the Calgary Comprehensive Epilepsy Programme and Director of Clinical Research at the Hotchkiss Brain Institute in Calgary, Canada.

Kinsmen Chair in Paediatric Neurosciences.

Primary Clinical and Research Activities: Broad areas of academic interest are outcomes and epidemiological research in epilepsy with notable contributions in surgical randomized trials, epidemiological studies, quality of life, and economics in epilepsy. Research endeavours overlap with evidence-based neurology, an area he has pioneered in North America through training programs and production of evidence-based practice guidelines. Dr Wiebe is an experienced epileptologist, focusing on medical and surgical management of complex epilepsies. He has mentored numerous national and international clinical and research trainees.

Significant Service Activity within the League: He has been active in ILAE activities for the last ten years. He is past-President of the Canadian League Against Epilepsy, currently chairs the ILAE North American Regional Commission, and is the Secretary to the Epilepsy Care Commission of the International League Against Epilepsy, which oversees activities of the Global Campaign Against Epilepsy. He has served on the ILAE Task Force on the Definition of Intractable Epilepsy and on the sub-committees on Quality of Life and Health Care Policy.

Emilio Perucca, Treasurer



Dr Perucca obtained his MD and a Specialization in Neurology at the University of Pavia in Italy, and a PhD at the University of London, where he trained as a clinical pharmacologist and neurologist. He is currently Professor of Clinical Pharmacology at the University of Pavia and Director of the Clinical

Trial Centre at the Institute of Neurology in Pavia.

Research Activities: His research interests have been focused on the treatment of epilepsy, with special reference to clinical pharmacokinetics, clinical trial methodology, and outcome assessment. He has authored many articles and textbooks on these topics. He serves on the editorial/advisory board of many journals, including *Epilepsia*, *Epileptic Disorders*, *Epilepsy Research*, *Seizure*, *CNS Drugs*, and *Lancet Neurology*.

Service to ILAE: Dr Perucca contributed actively to ILAE activities for over 20 years and has been a member of various Commissions, including those on Outcome Measurement, Therapeutic Strategies, and Education. Between 2001-2005, he served as Secretary to the Commission of European Affairs, and between 2005-2009 as First Vice President of ILAE. During the last four years he also chaired the Faculty of 1000 Task Force and coordinated ILAE activities in Africa. At a national level, he has been President of the Italian ILAE Chapter. In 1997, he received the Ambassador for Epilepsy Award, and in 1999 he was awarded honorary membership to the Polish Epilepsy Society.

Tatsuya Tanaka, First Vice President



Dr Tanaka is Professor Emeritus, Department of Neurosurgery, Asahikawa Medical College, Hokkaido, Japan. President of Japan Epilepsy Society (2005-2009). President of Hokkaido Epilepsy Society. Honorary Director, Yamabiko Medical Welfare Center, Kagoshima, Japan.

Primary Clinical and Research Activities: He started to develop an international perspective under Professor Robert Naquet in France (1973), when he studied basic research using techniques such as kindling and kainic acid-induced seizures. His international experience continued under Professor Andre Olivier at the Montreal Neurological Institute, where he acquired clinical experience in epilepsy surgery. His basic research background has been extremely important to his understanding of the pathophysiology of epilepsy, in order to develop therapeutic and surgical strategies for

(continued on page 21)

ELECTIONS REPORT *(continued)*

patients with intractable epilepsy. These experiences have resulted in more than 250 publications in English, French or in Japanese. He has mentored national and international clinical and research trainees.

Significant Service Activity within the League: He has been involved in ILAE activities for the last ten years. He was a member of the Commission on Neurosurgery (2001-2005) and served on the Commission on Asian Oceanian Association (CAOA) Task Force as a Chair of the Basic Research Committee. He is the current president of the Japan Epilepsy Society.

Michel Baulac, Second Vice President



Current Position: Professor of Neurology and Neuroanatomy at University Pierre et Marie Curie (Paris VI), Head of Neurology Department at la Pitié-Salpêtrière Hospital in Paris, APHP, Director of Epileptology Unit, and Coordinator of Epilepsy Research at the CRICM (Centre de Recherches-Institut du

Cerveau et de la Moelle, INSERM), Co-director of the National Centre for Rare Epileptic diseases (adults).

Primary Clinical and Research Activities: The epilepsy program at la Pitié-Salpêtrière includes all the medical and surgical aspects of epilepsy care, including genetics and clinical pharmacology.

Main Domains in Research: neurophysiology of post-operative tissues; structural and functional brain imaging, development of AEDs (methodological aspects); seizure emergence, pre-ictal changes and seizure prediction. Our group, (Eric Le Guern and Stephanie Baulac) contributed to the discovery of two major epilepsy genes SCN1A and GABRG2, our focus being now genetics of temporal lobe epilepsies.

Significant Service Activities within the League: Member (2001-2005) and then Chair (2005-2009) of the Commission on European Affairs, former Vice President of the French Chapter. This work included development of Epilepsy Congresses, an agenda of international courses across Europe, while dedicating parts of the European Budget to Extra-European activities. Some of them were run through EUREPA, and I am involved in the revision of the ILAE-EUREPA partnership. Managing the European Region means communication with more than 40 Chapters, motivation of sub-regional initiatives and synchronies, and allocating financial supports, primarily to the less-advantaged countries.

We also invested in other domains of general interest: establishing contact with the European Drug Agency, investing in consensus actions on Status Epilepticus, opening the concept of "rare" epileptic diseases, or promoting the funding for Epilepsy Research at the level of the EU institutions.

Michel Baulac, Vice President



Dr. Medina is professor of Neurology and Epileptology at the National Autonomous University of Honduras and has served as Chairman of the Education Subcommittee of the World Federation of Neurology. He performed his epileptology training at the Saint Paul Center, Marseilles, France, under the direction of Charlotte Dravet and

colleagues, and later at the University of California, Los Angeles (UCLA). After his return to Honduras he helped found the ILAE Honduras Chapter, and the Honduras Neurology Training Program at the National Autonomous University of Honduras, which was the first pilot educational program of the World Federation of Neurology. During the last 10 years this program has improved the epilepsy and neurological care in Honduras by reducing the incidence of epilepsy due to neurocysticercosis in rural areas of Honduras. As Professor and Director of the Neurology Training Program, he started an international collaborative research program with UCLA, Mexico, Japan, Central and South America on the search for the epilepsy genes, epidemiology of the epilepsies, and neurocysticercosis. Through this partnership, they have co-discovered the EFHC1 Juvenile Myoclonic Epilepsy gene and the GABRB3 Childhood Absence epilepsy gene, and established a community epilepsy intervention program in Salama, Honduras. In the last ten years Dr. Medina also worked with the Los Angeles Epilepsy Foundation.

During the last 8 years Dr Medina served as member of the ILAE Commission on Latin American Affairs, and as the Chairman of this Regional Commission. He helped found the Latin American Academy of Epilepsy (ALADE) and was honored to be elected the first president. This group has supported the education and research activities in our region as well as working with the ILAE Epilepsy Care Commission. Through these efforts, Latin America took big step forward, becoming a mature region: with periodic regional epilepsy congresses, the Latin American Summer School, the establishment of ALADE, establishment of new sub-commissions, like the epilepsy surgery sub-commission, and the collaboration with the ILAE North American Commission.

LOOKING INTO THE FUTURE

Planning for the Next 100 Years

In July 2009, during the 28th International Congress held in Budapest, Hungary, our League officially entered its second century. The League was inaugurated at a side meeting held during the XVIth International Medical Congress on 30 August 1909 in the Salle Donau of the Hotel Bristol, in the same city, Budapest. Forty-six people, mainly neurologists and psychiatrists, were present. The 4,000 people who were present at the 28th Congress had the opportunity to walk through an exhibit featuring the Hotel Bristol and the ILAE Centenary Exhibition. Indeed, ILAE members should be very proud of our accomplishments since our founding in 1909. With Chapters in over 100 countries, the ILAE has become the recognized society of medical and allied health professionals sharing the goal of improving the lives of persons with epilepsy throughout the world. For the League to get here, it took the personal effort and commitment of numerous individuals who volunteered their time in many capacities over the years.

Celebrations of historical achievements are an important opportunity to review the past and look toward the future in order to meet the challenges. The beginning of the League's second century offers us unprecedented opportunities to incrementally improve epilepsy care worldwide through a coordinated program of education, research and the development of centers of excellence. Epilepsy is a disorder afflicting humans for many millennia. There are detailed writings about its symptoms, causes, consequences and treatments even in ancient cultures. Some of the causes we now know are genetic in origin; some have remained unknown. Often epilepsy is related to structural/metabolic disorders. It is frequently associated with almost all conditions that affect our planet such as various infections (including HIV), malnutrition, intoxications, neoplasms, stroke, and traumatic brain injury. Prevention and prompt treatments are of paramount importance. Unfortunately, there are still many gaps not only in our knowledge but also in the availability of resources to deliver effective health care in many regions.

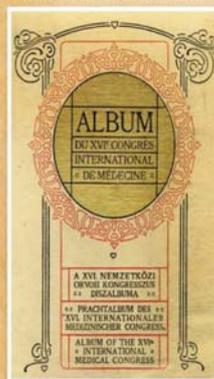
During the next four years (2009-2013), and, hopefully beyond, we will need to work together to:

- Enhance collaborative international education, training, and research to improve the quality of life for all persons with epilepsy,
- Foster initiatives to improve the medical care of people with epilepsy, by improving access to treatment which is limited or absent in many countries of the world, and

The XVIIth International Medical Conference Budapest, 1909

The International Medical Congresses series started in Paris in 1867 and continued until 1913. The XVIth meeting, in Budapest, ran from 29 August to 2 September 1909, and was a grand affair. Over 5,000 delegates attended, and witnessed the entrance of his Royal and Imperial Highness the Archduke Joseph sweeping down the redoubt. Every congress member was given a scholarly medical guide to Budapest, a ticket for free use of the local baths and a fine bronze medallion designed by the sculptor György Vastagh.

As Cushing recorded in his diaries, the welcoming reception was something of a zoo, teeming with 'males...not too wrapped up in the affairs of science...who did not hesitate to push and struggle, to climb and crawl...to arrive at the refreshment tables'. European politics were evident, for example in a boycott of the congress by the Romanians over an issue of race and language. The English delegates found themselves the target of some disapproval when a letter from the Anti-alcohol Association, signed by Sir Victor Horsley, urged congress members to refuse the two small bottles of Tokaj wine offered as a gift from the Hungarian Ministry of Agriculture. There were many soirees and a performance at the national theatre of Madách's 'Tragedy of Man' (an apt title, given the course of European history in the next few decades).



- Identify, mentor and develop the next generation of League leaders.

To achieve this, we have already taken the following initial steps:

Establish a Strategic Plan. The Strategic Plan (www.ilae.org) created by a specially commissioned Task Force was approved by the Executive Committee and is now posted on the Web site. It becomes the template for ILAE activities for the next four or more years. Gary Mathern will chair the newly-constituted Strategic Plan Task Force to develop measurable outcomes, facilitate interactions among regional and

(continued on page 23)

LOOKING INTO THE FUTURE *(continued)*

topic-oriented Commissions and advise the Executive Committee on action items.

Disseminate the League's message and augment the delivery of information. When compared to other disorders, epilepsy does not get the recognition as an important medical and scientific issue. Our goal will be to raise the awareness and importance of epilepsy and epilepsy research. This can be achieved by effective partnerships with WHO, IBE and other influential organizations.

One example of our efforts to raise the visibility of epilepsy was our collaboration with UEFA during the recent European football championship for players under 21 years of age held in Sweden. This event, co-organized with the Commission on European Affairs, consisted of two short football matches played by teams of athletes with epilepsy from all over Europe, just before the European Championship semi-finals kick off on 26 June 2009. The teams also included several top-level former professional footballers, who generously agreed to come to Gothenburg and Helsingborg to support our cause. The League has sent letters to the UEFA leadership expressing our heartfelt gratitude and deepest appreciation for organizing this memorable football event that raised public awareness on the plight of all those individuals afflicted with epilepsy.

Similar initiatives will contribute to improving knowledge about epilepsy and, most importantly, emphasize that people with epilepsy are entitled and able to live a life that meets their expectations and to engage fully in social and professional activities.

Most importantly, almost 30% of all people with epilepsy continue to have seizures despite our efforts and incremental knowledge. Consequently, we need to emphasize to governmental organizations and other agencies the importance of innovative research to prevent and cure epilepsy. Ed Bertram, our Information Officer is spearheading this effort to promote the epilepsy-related agenda in research. To this end, each Commission and Task Force has a designated information officer who will work with Ed.

Amend the Constitution to ensure wide regional representation. Because the needs in each country are different, we have to develop a method for evaluating each situation and for developing a country appropriate plan. To identify the varying regional conditions and needs, it is essential that each Region have a voice and strong representation at the level of

the League's Executive Committee. For this reason it is important to look at our Constitution to ensure that each Region is well represented. Our three Vice Presidents, Tatsuya Tanaka, Michel Baulac and Marco Medina together with Simon Shorvon will review and update the constitutional proposals that Emilio Perucca and I drafted during the past four years and submit a comprehensive proposal to be voted on at the Assembly held in 2011 in Rome. If approved, this Constitution will also serve as the blueprint for the Constitutions of our Regional Commissions so that we all work together under the same conditions.

Develop a cohesive program for the Global Campaign. The goals of the Global Campaign include dissemination of information on the magnitude, burden, diagnosis and treatment of epilepsy and available resources; support to governments and health care providers in formulating and implementing comprehensive services, by offering successful models of epilepsy care; support to countries in fighting stigma and discrimination; and support for research capacity in developing countries. The current Global Campaign efforts are led by a Secretariat consisting of a member of the ILAE, a member from IBE and one from the WHO. Because the success of the Global Campaign is of paramount importance to both the Bureau and the League, the two respective Presidents, Mike Glynn and I, will lead the effort as members of the Secretariat, together with Dr Tarun Dua (representing the WHO) and will follow the recommendations of the endorsed Strategic Plan. Ms Hanneke de Boer will serve as the Coordinator for the Secretariat of the Global Campaign Against Epilepsy and will report directly to the respective Executive Committees.

We look forward to very active collaboration among the Executive, the Commissions and you. Indeed, the keyword to accomplish our goals is we: the members of our Society. The League in turn is developing mechanisms to recognize your selfless contributions as you volunteer to work the extra hours it takes in your very busy professional lives. All the plans in the world will go nowhere without the efforts of the membership, and we will be counting on all of our efforts to make this world a better place for people with epilepsy.

Solomon L Moshé
Incoming President



Regional Commissions

COMMISSION ON ASIAN AND OCEANIAN AFFAIRS (CAOA)

List of Members and Officers:

As of June 2009, CAOAA takes charge of 15 Chapters in the Asian Region (Bangladesh, China, Hong Kong, India, Indonesia, Japan, South Korea, Malaysia, Mongolia, Nepal, Pakistan, Philippines, Singapore, Taiwan, and Thailand) and two Chapters in the Oceanic Region (Australia and New Zealand). New Zealand's Chapter was accepted in 2007 at the ILAE General Assembly held during the 27th IEC in Singapore. The Vietnam Chapter, formed in early 2008, will be formally accepted in July 2009 during 28th IEC in Budapest. Sri Lanka is in the process of forming a Chapter.

Before May 2006, the CAOAA was administered by the officers of 2001–2005. Nomination and election of the CAOAA 2006–2009 Officers was carried out in the last quarter of 2005. New members of CAOAA took office officially in May 2006. The composition of CAOAA is shown in Table 1.

Table 1: Officers of CAOAA (2006-2009)

Chairman	Shih-Hui Lim (Singapore)
Secretary	David Reutens (Australia)
Treasurer	Patrick Kwan (Hong Kong)
Members	Leonor Cabral-Lim (Philippines) Satish Jain (India) Shichuo Li (China) Kazuichi Yagi (Japan)
Ex-Officio	Chong Tin Tan (ILAE-VP and ASEPA Chairman)

The Asian Epilepsy Academy (ASEPA) was formed in 2003, initially as the educational arm and now a sub-commission of CAOAA. The composition of ASEPA is shown in Table 2.

Table 2: Officers of ASEPA (2003-2007 and 2007-2011)

Office Bearers	ASEPA 2003 – 2007	ASEPA 2007 – 2011
Chairman	Masakazu Seino (Japan)	Chong-Tin Tan (Malaysia)
Secretary	Simon Harvey (Australia)	Andrew Bleasel (Australia)
Members	Satish Jain (India) Shih-Hui Lim (Singapore) Guoming Luan (China) Byung-In Lee (Korea)	Gourie Devi (India) Yushi Inoue (Japan) Weiping Liao (China)
Ex-Officio	Peter Wolf (EUREPA Rep) Chong Tin Tan (CAOA Chair)	Peter Wolf (EUREPA Rep) Shih-Hui Lim (CAOA Chair)

Aims of CAOAA:

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

Missions of CAOAA and ASEPA:

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

Commission Activities:

1. Communication and Business Meetings

Communication among members of CAOAA and ASEPA were mainly through e-mails and during teaching courses/workshops. In addition, CAOAA and ASEPA had joint business meetings at least once a year as shown below:

- 29 July 2006, in conjunction with the meeting of the IOC and SAC of the 6th Asian Oceanian Epilepsy Congress (AOEC) in Kuala Lumpur, Malaysia;
- 15 November 2006, during the 6th AOEC in Kuala Lumpur, Malaysia;
- 10 July 2007, during the 27th International Epilepsy Congress (IEC) in Singapore;
- 15 May 2008, during the 7th AOEC in Xiamen, China.

The next business meeting will be held on 29 June 2009, during the 28th IEC in Budapest, Hungary.

2. Chapter Conventions

Two Biennial Chapter Conventions were held during AOECs: (1) 16 November 2006, 11:30 a.m. to 2:00 p.m., during 6th AOEC at the Kuala Lumpur Convention Center, Kuala Lumpur, Malaysia, and (2) 15 May 2008, 11:30 a.m. to 2:00 p.m., during 7th AOEC at the Seaview Hall of the Xiamen

(continued on page 26)

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

International Conference and Exhibition Centre (XICEC), Xiamen, China. National delegates from the ILAE Chapters in this Region participated in these two Conventions. In addition, representatives from non-Chapter countries including New Zealand (before joining ILAE), Vietnam (joining ILAE in 2009), Sri Lanka, Laos, Myanmar, and Brunei were invited and/or attended the Conventions.

3. Organization of 7th Asian Oceania Epilepsy Congress (AOEC)

The 7th AOEC was successfully held in Xiamen, China, from 15 to 18 May 2008. Most members of CAOAA and ASEPA were members of International Organizing Committee (IOC) and Scientific Advisory Committee (SAC). The Congress was attended by 1800+ delegates, the largest number of all AOECs. If not because of the devastating earthquake in Sichuan, China, the attendance would have been higher. The Congress also received the highest number of abstracts, and accepted 445. There were 73 regional and eight non-regional speakers. Ms Kathryn Hodgson was the main person from the IDM office to provide all the important secretariat support. CAOAA assisted IOC and SAC in awarding bursaries for those who submitted an abstract as well as those who did not submit an abstract for the Congress. The Inaugural Masakazu Seino Memorial Lecture, a Chinese Language Session, a pre-AOEC teaching course on Translational Research, four Tadokoro's Awards, and a special session on "Renaming" the Chinese word for epilepsy, were the highlights of the Congress.

4. Research Task Force

As part of the mission of CAOAA, a Research Task Force was formed during the 6th AOEC to explore the feasibility of joint research. Headed by Dr Patrick Kwan from Hong Kong, the Task Force identified research priorities for the Region. Members of the Task Force were divided into different sub-groups to focus on specific areas within epileptology. Table 3 shows the list of participants according to their specialties and interests. The Task Force met for discussion in Singapore on 12 July 2007 during the IEC, and presented their proposal for joint research on 18 May 2008 during AOEC in Xiamen. The goal is to have a unified document produced by the end of 2009.

Table 3: CAOAA Research Task Force

Sub-Group: Epidemiology
Sub-Group Coordinator: W D'Souza (Australia)
Members: J P Agrawal (Nepal), L Cabral-Lim (Philippines), S Jain, P Kwan (Hong Kong), W P Liao (China), M Mannan (Bangladesh), Z Mogal (Pakistan), A Tovvudorji (Mongolia), A Visudtibhan (Thailand)

Sub-Group: Pharmacology
Sub-Group Coordinator: S Jain (India)
Members: J P Agrawal, P Bergin (New Zealand), L Cabral-Lim, P Kwan, B I Lee, W P Liao, M Mannan, D J Yen

Sub-Group: Psychosocial / QOL / Public Health
Sub-Group Coordinator: K S Lim (Malaysia)
Members: L Cabral-Lim, W D'Souza, M Mannan, Z Mogal

Sub-Group: EEG
Sub-Group Coordinator: S Y Kwan (Taiwan)
Members: S Gunadharma (Indonesia), M Mannan, S H Lim (Singapore)

Sub-Group: Surgery
Sub-Group Coordinator: T Tanaka (Japan)
Members: B I Lee, P Bergin

Sub-Group: Basic Science/Genetics
Sub-Group Coordinator: B I Lee (Korea)
Members: S Jain, P Kwan, W P Liao, N Tan (Singapore), T Tanaka

5. Establishment and Delivery of Masakazu Seino Lecture

Dr Masakazu Seino, a distinguished Epileptologist, past Chairman of CAOAA (1996-2001), Chairman of ASEPA (2003-2007), Founding Chairman of the Asian Oceanian Epilepsy Organization, and Past Vice President of ILAE, passed away on 7 April 2007. On the day of his death, he was still communicating with one of the CAOAA members on the future and financial support of ASEPA. Dr Seino's family, together with his friends, colleagues and the Japan Epilepsy Society, held a memorial service at Hotel New Ohtani, Tokyo Japan on 8 April 2007. Dr Solomon Moshé, Secretary-General of the ILAE, Dr Shih-Hui Lim, Chairman, CAOAA and Dr Chong Tin Tan, ASEPA Chairman attended the service.

To perpetuate the memory of the Late Dr Seino and to recognize his immense contributions to the field of Epileptology in the World, CAOAA-ASEPA established a biennial lectureship in the name of Dr Seino, to be delivered at each AOEC. The inaugural "Masakazu Seino Memorial Lecture" was delivered by Dr Yuko Fukuyama during the 7th AOEC in Xiamen in 2008. Dr Kazuichi Yagi also spoke on Dr Seino. The memorial lecture was sponsored by Dainipon-Sumitomo and Eisai.

(continued on page 27)

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

6. Global Campaign Against Epilepsy (GCAE) Activity in Laos

There is progress in reducing the epilepsy treatment gap in Laos. The French Institute of Tropical Medicine in Vientiane, Laos has obtained the support from Sanofi to supply free drugs in Laos. CAO A assisted in this project and will work with the European Commission, Japan Epilepsy Society, Taiwan Epilepsy Society and the Peter Wolf Foundation to support this project financially.

Accomplishments:

1. Organizing and Conducting Teaching Courses and Workshops

Under the leadership of Dr Chong Tin Tan, ASEPA planned, organized and/or conducted a number of teaching courses and workshops, either as standalone meetings with the local host, or as part of the national or regional medical conferences such as the Biennial Conventions of the ASEAN Neurological Association (ASNA) and AOECs. These workshops and teaching courses covered the following topics: General Epileptology, EEG, AED Treatment, Epilepsy Syndrome, Neuro-imaging, Pediatric Epileptology, Epilepsy Surgery, Basic Sciences, and Psychosocial Issues. A Winter School was initiated by the Melbourne group of Epileptologists. Table 4 (page 29) gives the details of these courses and workshops.

2. Awarding Fellowship

Every year, two Clinical Fellowships were awarded by CAO A-ASEPA. In addition, ASEPA assisted in the award of two six-month Fellowships of the Epilepsy Research Foundation of Japan and one 12-month Fellowship from Epilepsy Society of Australia. Successful candidates from China, Bangladesh, India, Myanmar, Vietnam, Sri Lanka, and Indonesia underwent training in Shizuoka, Japan; Melbourne, Australia; Trivandrum, India; Singapore and Kuala Lumpur, Malaysia.

3. Improving Standard of EEG Interpretation and Reporting

ASEPA together with the ASEAN Neurological Association (ASNA) launched an EEG certification examination in 2005, to establish and improve the standard of training and professional practice of EEG in Asia. To be certified as a qualified Electroencephalographer, candidates have to pass Part 1 and 2 of the Examination, both conducted in English. Part 1 is a written examination testing the knowledge of EEG instrumentation, normal and abnormal EEGs. Candidates have to answer 150 multiple-choice questions in three hours. Part 2 is an oral examination, testing the skills of routine EEG recording, reporting and interpretation, by a panel of examiners who are either diplomats of the

American Board of Clinical Neurophysiology and/or have extensive experience in using routine and long-term EEG monitoring.

Drs Shih-Hui Lim (Singapore), Andrew Bleasel (Australia) and Akio Ikeda (Japan) are the Chief Examiners of this EEG Certification Examination. Other examiners were from Australia (Simon Harvey, John Dunne, Ernie Somerville, Terrence O'Brien and Mark Cook), Malaysia (Chong Tin Tan, Raymond Ali), Singapore (Andrew Pan, Einar Wilder-Smith, Nigel Tan and Derrick Chan), Japan (Inoue Yushi), Taiwan (Shang-Yeong Kwan), Germany (Alois Ebner), and USA (Prakash Kotagal).

Ninety candidates from Hong Kong, Indonesia, India, Japan, Malaysia, Singapore, Thailand and Vietnam have taken the Part 1 Examination, conducted during ASNA Conventions (in Jakarta, Indonesia 2005, Cha Am, Thailand 2007, and Kuala Lumpur, Malaysia 2009), AOECs (in Kuala Lumpur, Malaysia 2006 and Xiamen, China 2008) and the International Epilepsy Congress (Singapore 2007). The passing rate was approximately 60%.

Twenty-one candidates have taken the Part 2 Examination, conducted during AOECs (Kuala Lumpur, Malaysia 2006 and Xiamen, China 2008), IEC (Singapore 2007) and ASNA Convention (Kuala Lumpur 2009). All passed the Part 2 Examination (one candidate after 2nd attempt) and have been certified as Electroencephalographers. Of these, five were EEG technologists.

4. Publishing Proceedings of Scientific Conferences

The Proceeding of the 6th AOEC, which consisted of presentations of the plenary sessions, symposiums, and 40 selected abstracts from free papers, was published in 2007 as a supplement of *Neurology Asia*. Another Proceeding on the "Current status of epilepsy surgery in Asia," also published as a supplement of *Neurology Asia* in 2007, was based on presentations at the workshop on epilepsy surgery in Shizuoka, Japan, 2006. The publication is sponsored by UCB Japan. Both supplements can be accessed online in www.neurology-asia.org.

Future Work:

Myanmar, N Korea, Laos, PNG, Fiji and Timor Leste are the countries in the Asian & Oceanian Region with significant populations without a national epilepsy organization and/or an ILAE Chapter. This reflects slow development of epilepsy care in these countries. Even in those countries with ILAE Chapters, varying degrees of knowledge, research and/or treatment gaps still exist.

(continued on page 28)

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

CAOA-ASEPA is not likely to have any meaningful influence on the economy and political situations in this part of the world. However, as a strong medical professional group, CAOAA-ASEPA could improve the standard of practice of epileptology in this region. We will build upon the foundation laid by our predecessors and create new initiatives to further strengthen the training and education of healthcare providers. CAOAA-ASEPA will continue to do its part to minimize knowledge gaps by increasing its educational effort in as many cities/countries as possible. It is also hoped that the Research Task Force will help to narrow the research gap, thereby indirectly improve patient care. Cooperation and collaboration with IBE-RECs, regional offices of World Health Organization, and regional neurological organizations need to be increased to further reduce treatment gaps in this region. Members of the CAOAA-ASEPA are now working closely with our IBE-Regional Executive Committees and the Epilepsy Society of Australia to organize the 8th AOEC which will be held in Melbourne, Australia in October 2010. The 9th AOEC is likely to be held in the Philippines and CAOAA-ASEPA will continue to play a significant role in the organization.

Smooth leadership transition and well thought succession planning are extremely important for any professional organization to excel in a constantly changing environment. We are pleased that the next ILAE Executive Committee led by the current President-

Elect Dr Solomon L Moshé have begun their hard work in preparing a smooth leadership transition, especially for the Asian & Oceanian Region. We are most pleased that Dr Byung-In Lee from Korea will be leading the next CAOAA from 2009 to 2013. Dr Lee is one of the Founders of the Asian Oceanian Epilepsy Organization and is an eminent epileptologist in this Region. With his leadership, passion and vision, we are certain that CAOAA-ASEPA will reach a greater height.

Summary:

CAOA-ASEPA had a busy but fruitful 3+ year term. With our part-time involvement but full-time dedication, we managed to maximize the usage of limited human and financial resources to improve the standard of epilepsy care in this Region which has the largest population of people with epilepsy. With the commitment and sacrifices of previous and current members of CAOAA-ASEPA and the strong support of ILAE and many epileptologists in this Region, we are glad to have accomplished our two main missions, i.e., (1) to advance and disseminate throughout the Asian & Oceanian Region knowledge concerning the epilepsies, and (2) to improve education and training in the field of the epilepsies in Asia.

Shih-Hui Lim
Chair

(continued on page 29)

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

Table 4.

Type of Courses and Workshops	Dates	City, Country	Teaching Faculty	Sponsoring Organization
<i>General Epileptology</i>	15-16 June 2006	Nanning, China	W P Liao (China), C T Tan (Malaysia), J J Tsai (Taiwan), K Yagi, Y Inoue, Y Takahashi & M Seino (Japan)	ILAE-CAOA
	20-21 April 2007	Haikou, China	W P Liao (China), S H Lim (Singapore), C T Tan (Malaysia), K Yagi & Y Inoue (Japan)	ILAE-CAOA
	11-12 January 2008	Fuzhou, China	W P Liao (China), S H Lim (Singapore), C T Tan (Malaysia), Y Inoue (Japan)	ILAE-CAOA
<i>EEG</i>	17-18 February 2006	Dhaka, Bangladesh	A Pan (Singapore), A Mohamed (Australia), K Terada (Japan), C T Tan (Malaysia)	ILAE-CAOA
	14 November 2006 (during 6th AOEC)	Kuala Lumpur, Malaysia	SH Lim & A Pan (Singapore), A Bleasel (Australia), A Ikeda, K Terada (Japan), C T Tan (Malaysia)	ILAE-CAOA
	6 March 2007 (during 6th ASNA Convention)	Cha Am, Thailand	S H Lim (Singapore), A Ikeda, (Japan), Y Chinvarun & T Desugitkol (Thailand), C T Tan (Malaysia), J Dunne (Australia)	ILAE-CAOA
	13-15 June 2008	Hanoi, Vietnam	S H Lim (Singapore), S Harvey (Australia), CT Tan (Malaysia), H Okada (Japan)	ILAE-CAOA
	25-27 September 2008	Tianjin, China	W P Liao (China), S H Lim (Singapore), A Bleasel (Australia), A Ikeda, N Akamatsu (Japan), C T Tan (Malaysia), S Y Kwan (Taiwan)	UCB-Japan & CAEE
	3-4 October 2008	Colombo, Sri Lanka	S H Lim (Singapore), C T Tan (Malaysia), J Wanigasinghe, S Gunasekara & P Ratnayake (Sri Lanka)	ILAE-CAOA
	17 November 2008	Hong Kong SAR, China	S H Lim (Singapore), K Terada, (Japan), CT Tan (Malaysia), M Kiley (Australia)	ILAE-CAOA & Hong Kong Epilepsy Society
	1 April 2009 (during 8th ASNA Convention)	Kuala Lumpur, Malaysia	A Bleasel, S Harvey (Australia), S H Lim, D Chan (Singapore), C T Tan (Malaysia)	ILAE-CAOA & ASEAN Neurological Association
<i>Neuroimaging</i>	25 February 2006	Guangzhou, China	D C Reutens, G Jackson & J L Freeman (Australia)	Epilepsy Society of Australia
	16 September 2007	Bacolod, Philippines	D C Reutens, & J L Freeman (Australia), K Tan (Philippines)	Epilepsy Society of Australia
<i>Pediatric Epileptology</i>	29 September 2007	Kathmandu, Nepal	H Shinichi (Japan), L C Ong (Malaysia), V Udani (India), S Harvey (Australia), N Bajaj (Nepal)	ILAE-CAOA
	2 October 2007	Mumbai, India	H Shinichi (Japan), L C Ong (Malaysia), V Udani (India), S Harvey (Australia), R Kuzniecky (USA)	ILAE-CAOA

(continued on page 30)

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

Type of Courses and Workshops	Dates	City, Country	Teaching Faculty	Sponsoring Organization
Surgery	8-10 March 2006	Shizuoka, Japan	Y Inoue, A Ikeda, S Kameyama & T Otsuki (Japan), B I Lee (Korea), T T Wong (Taiwan)	UCB Japan
	20-22 September 2007	Xian, China	Y Inoue, A Ikeda, T Tanaka, T Otsuki, K Baba & K Terada (Japan), B I Lee & S A Lee (Korea), T T Wong & Y H Shih (Taiwan), S H Lim (Singapore), X Z Liu (China)	UCB Japan
	22-23 August 2008	Semarang, Indonesia	Y Inoue, K Iida, K Arita, T Otsuki, (Japan), Z Muttaqin (Indonesia), S A Lee (Korea), S H Lim (Singapore), S Harvey (Australia), C T Tan (Malaysia)	UCB Japan, PERPEI (ILAE Chapter) & Indonesia Neurological Association
Epilepsy Syndrome	27-28 April 2007	Bandung, Indonesia	E Somerville, A Bleasel & J Dune (Australia), N Tan (Singapore), A Berroya (Philippines), R Panggabean (Indonesia)	UCB Asia-Pacific
	29 February-1 March 2008	Dhaka, Bangladesh	E Somerville, J Dunne, W D'Souza, L Nagarajan (Australia), C T Tan (Malaysia)	ILAE-CAOA
	2 April 2009 (during 8th ASNA Convention)	Kuala Lumpur, Malaysia	J Dunne, S Harvey, T O'Brien (Australia), S H Lim, D Chan (Singapore), T B Khoo (Malaysia), M H Ortiz (Philippines)	ILAE-CAOA & ASEAN Neurological Association
Psychosocial Issues	26-27 May 2007	Shanghai, China	J J Tsai & S L Lai (Taiwan), A Tovvoudorj (Mongolia), A Hung (Hong Kong), H Kubota (Japan), Z Hong, Wang & Li (China), C T Tan (Malaysia)	IBE-Regional Executive Committees for Western Pacific & South-East Asia Regions and ILAE-CAOA
Basic Sciences	7 July 2007 (during 27th IEC)	Singapore	T O'Brien, S Petrou, J Willoughby & G Jackson (Australia), G W Mathern, A Galanopoulou, E H Bertram & S L Moshe (USA), K Yamakawa (Japan)	ILAE-CAOA
	14-15 May 2008 (during 7th AOEC)	Xiamen, China	E Cavalheiro (Brazil), B I Lee, H S Shin (Korea), P Wolf (Denmark), I Scheffer (Australia), G Avanzini (Italy), T Tanaka (Japan), T Su (China), P Satishchandra (India)	ILAE's Subcommission on Basic Research of the Educational Commission
Epilepsy Winter School	16-20 June 2008	Melbourne, Australia	S Berkovic, T O'Brien, I Scheffer, S Harvey, G Jackson, S Bowden, S Adams, O Alvarez, M Cook, F Vajda (Australia)	Epilepsy Society of Australia & GSK-Australia
AED Treatment	7-8 April 2006	Guangzhou, China	P Kwan (Hong Kong), S H Lim (Singapore), M Cook & D McLaughlin (Australia), W P Liao (China), C T Tan (Malaysia)	UCB Asia-Pacific
	5-6 September 2008	Tagaytay, Philippines	P Kwan (Hong Kong), L Cabral-Lim, Perez-Gosengfiao, & M H Ortiz (Philippines), S H Lim (Singapore), M Cook (Australia), C T Tan (Malaysia)	UCB Asia-Pacific

COMMISSION ON EASTERN MEDITERRANEAN AFFAIRS (CEMA)

Aims:

- Promote epilepsy education by organizing epilepsy courses
- Epilepsy care and patient education
- Translational research
- Increase the number of Chapters in the Region

Commission Activities from 1 January 2008 until 31 May 2009:

Commission Activities in 2008

- Epilepsy Course on TLE in Jeddah, January 2008
- Epilepsy Course in Cairo, Egypt, 12 February 2008
- Epilepsy Course in Tripoli, Libya, 22-24 February 2008
- EEG Course in Jeddah, 20-22 March 2008
- Epilepsy Course in Tunis, Tunisia, 27-28 March 2008
- Epilepsy Course in Sanaa, Yemen, 20 April 2008
- Epilepsy Course in Muscat, 21 May 2008
- Pediatric Epilepsy Course in Riyadh, 22-24 November 2008

Commission Activities in 2009

- EEG Course in Cairo, Egypt, 15-16 January 2009
- Epilepsy Course in Sanaa, Yemen, 15 March 2009
- Pediatric Epilepsy Course in Alexandria, Egypt, 23-25 April 2009

Accomplishments:

- New Eastern Mediterranean Chapters are being established. Currently the Libyan, Yemeni and Sudanese Chapters are being formed
- Organizing the 2nd CEMA Congress in Marrakech, Morocco 12-15 November 2009

Recommendations for Future Work:

- Establishment of the East Mediterranean Academy for the Region.
- Basic epilepsy courses should be organized to raise the standard of the local neurologists.
- Publication of a regional newsletter.

Hassan Hosny
Chair

COMMISSION ON EUROPEAN AFFAIRS (CEA)

List of Members:

Milda Endziniene (Lithuania)
Alla Guekht, Advisory Council Chair, (Russia)
Cigdem Ozkara, CEA Secretary, (Turkey)
Bettina Schmitz (Germany)
Michel Baulac, CEA Chair, (France)
Meir Bialer, CEA Treasurer, (Israel)
Peter Halasz (Hungary)
Svein Johannessen, Advisory Council Co-Chair, (Norway)
Frederico Vigevano (Italy)
Peter Wolf, EC representative and EUREPA Chair
Giuliano Avanzini, EUREPA Chair

First of all, the outgoing CEA would like to thank the European Chapters for their trust and excellent partnership; the ILAE President, Peter Wolf, as well as the ILAE Executive and Management Committees for their support and understanding; the ILAE Financial Office, with a special mention for Donna Cunard; the headquarters office in Brussels; and the IDM for their excellence in Congress preparation and organization. Last but not least, EUREPA was a permanent partner in our educational activities. We also would like to express our gratitude to all the persons from our community who helped us on many occasions in working groups, task forces, scientific advisory and organizing committees for our Congresses or educational courses.

Education:

At the beginning of our term, we elaborated a comprehensive program of international educational courses, with the preoccupation of offering varied topics, including general epileptology, genetics, surgery, clinical pharmacology, and of trying to cover our vast geographical Region. Some of them were entirely organized and financed by the CEA, while others were only co-organized and co-financed by the CEA.

The Pharmacological Treatment of Epilepsy

2006:
2007: Israel (Eilat)
2008:
2009: Israel (Eilat)

Migrating Course

2006:
2007: Serbia
2008: Lithuania
2009: Czech Republic

Contribution to other courses

2006: San Servolo St Petersburg
2007: San Servolo Baltic Sea (Lithuania)
2008: San Servolo Baltic Sea (Denmark) Caucasian (Armenia)
2009: Baltic Sea (Kiel, Ger) Caucasian (Georgia)
San Servolo Moscow-Kazan

EPODES (Surgery)

2006:
2007:
2008: Brno
2009:

General Comments and Recommendations:

1. A database of students has been started in collaboration with EUREPA;
2. Pharmacological treatment of epilepsy: The 2003 San Servolo Course on this topic was successfully replicated by the CEA in Eilat in 2005 and 2007, with the same expectations for 2009. This topic is particularly important in Europe considering all the different new AEDs introduced on the markets, and the site of Eilat has proven to be very attractive to the trainees. Recommendation is to keep this important course topic on the CEA agenda;
3. Migrating Course on Epilepsy (MCE): The course takes place once a year in different European countries in collaboration with the CEA and EUREPA. So far, courses have taken place in Babe, Serbia 2007; Trakai, Lithuania 2008; and Pruhonice, Czech Republic 2009. The outgoing Commission would like recommend taking the program to Roma for 2010, and to pursue this program as a function of the needs. The principle is of a series of clinically oriented courses targeted to specialists at the second and third level of epilepsy care and focused on comprehensive aspects of diagnosis and treatment of epilepsy. It includes lectures on the clinically relevant aspects of epileptology and interactive case discussions and/or tutorials, including video-EEG sessions;
4. Advanced Summer School: This international course, usually in San Servolo, has become a major event for the international epileptology community. It has very strong European roots, as well as EU financial support, and it seems logical that the CEA remain an active partner;
5. Baltic Sea Summer Schools on Epilepsy (BSSSE) This program has been a success, the contribution from the CEA having been less substantial, so far.

Some reflection should be taken perhaps in order to adapt our best offerings to the actual needs of the different parts of the Region.

EUREPA:

A well-detailed and comprehensive business plan was endorsed by the CEA. It includes a program of activities including VIREPA (distance education), information and knowledge Web portals, training the trainers, accreditation, certification, bursary database and the financial aspects and implications in the present difficult context.

(continued on page 33)

COMMISSION ON EUROPEAN AFFAIRS (CEA) *(continued)*

As of the current situation, the relationships between EUREPA, ILAE and CEA have not been fully clarified. Particularly, the respective responsibilities from the CEA and from the ILAE regarding the functioning of EUREPA in the future should be refined. EUREPA is in a transition period, and on the other hand, the current EC and CEA are at the end of their term, therefore it was felt that the CEA was not in a position to make major decisions, and that any major decision concerning the future of EUREPA should be made through a close cooperation between the next upcoming EC and CEA. The budgetary issues, namely what would be the financial contribution from the CEA to the EUREPA budget (running budget in particular), will be crucial.

Congresses: (European Congress on Epileptology –ECE)

Two ECEs took place during our term, the 2006 Helsinki ECE (although prepared by the precedent CEA) and the 2008 Berlin ECE. Both were a great scientific success, and generated substantial surpluses. The important role of the SAC and their Chairs, R Kalviainen and C Elger together with M Bialer, should be emphasized

Two innovations:

1. The satellite in St Petersburg in 2006, inspired by the geographic proximity from Helsinki, which was an occasion to run a two-day course in Russia, very well attended;
2. The joint organization between the Israeli and the German Chapters in Berlin (2008).

Our Commission took in charge two selection processes: selection of Greece with Rhodos in 2010, and UK (city to be finalized between Glasgow and London). At these two occasions Turkey (Istanbul) finished in second position.

Recommendation:

1. Turkey is encouraged to bid again for ECE organization, and the high quality of the Turkish project will be emphasized to the next upcoming CEA. Of note, Greece was in the same situation at the beginning of the present CEA term, and ended up successful for the 2010 ECE;
2. The CEA tried to encourage joint organization by two Chapters. The joint (equally-partnered) Israeli-German organization in Berlin was a good example. Other possibilities exist. For instance, UK (selected for 2012) and Ireland are planning to cooperate in the 2012 ECE. In the current difficult financial context, however, the outgoing CEA would recommend that any type of joint organization should not lead to increased costs or plethoric IOC/SAC;
3. Communication with Chapters: This was mainly done on the occasion of the European Chapter

Conventions, in Helsinki 2006, Singapore IEC 2007, and Berlin 2008. The European Advisory Council chaired by Alla Guekht and Svein Johannessen, together with the Commission, suggested organizing the Convention of European Chapters on a yearly basis, including a Convention at the IEC. Care was taken not to overlap onto the global ILAE activities, and to the contrary, we encouraged our Chapter representatives to take active part in the ILAE activities during the IEC. The fact of providing financial assistance to representatives from the less advantaged countries should also be regarded as a CEA contribution to the global ILAE activities.

In the present period, 2005-2009, the priorities for EAC activities have been:

- Education (in close cooperation with EUREPA and the ILAE Commission on Education)
- Improvement of epilepsy care targeting the adequate management being accessible to all patients in all countries
- Regional and interregional cooperation between the European Chapters, forming the “European working networks” in specific areas of epilepsy care and research
- Special attention to the particular needs of different Chapters

Attendance:

Madrid, 2002 : 20 Chapters
Vienna, 2004 : 26 Chapters
Helsinki, 2006 : 40 Chapters
Singapore, 2007 (IEC): 31 Chapters
Berlin, 2008: 39 Chapters

CEA Rules and Statutes:

Two working groups have drafted an update of CEA rules and statutes, and a guideline for seeking CEA support for educational activities. The constitutional amendment proposed by Nico Moshé, if voted in Budapest, may lead to some substantial changes in the CEA/EAC rules, and to harmonize to some extent the CEA rules and Statutes with those of the other Regional Commissions. The process for the CEA election in May 2009 will follow the same principles as before, with some improvements regarding the safety and follow-up of the ballots sent by the Chapters. Participation by all is encouraged.

Care Standards:

- The relationships between EMEA (European Medicine Agency) and CEA: Through our contact group and during the post-Eilat Conference workshop on regulatory issues (June 2008), the views of our scientific community have been well received by the EMEA regulators. We can hope that some of our suggestions will be implemented in the

(continued on page 34)

COMMISSION ON EUROPEAN AFFAIRS (CEA) *(continued)*

next revision of the EMEA guidelines on AEDs. Several changes are expected regarding pediatrics syndromes in particular. This revised draft will be available through the Internet for consultation soon, and then there will be a few months for further comments. The EMEA regulatory rules and procedures are influencing drug availability and epilepsy therapy throughout Europe.

- Colloquium on Status Epilepticus: Our Commission invested in the two Colloquia, London 2007 and Innsbruck 2009, and its members participated actively in these enterprises aiming not only at refining knowledge on SE, but also at harmonizing treatment guidelines and drug availability across the Region. A guideline for treatment recommendation was published (*Epilepsia* 2008;49:1277-285). The CEA could play a coordinating role in future pan-European clinical trials in SE.
- Generics: Discussion groups on this topic were held during the Chapter Conventions, with very active participation showing that the issue of generics is throughout our Region, with various viewpoints.
- EPODES is a program designed to facilitate the development and the availability of epilepsy surgery programs in the less advanced parts (in this regard) of the Region. This program features courses, professorships (they will visit centers and train on-site candidate centers) and fellowships for training young epileptologists abroad. The registrations so far have suggested a high level of interest, and this activity should be pursued in 2010 (because of budgetary restrictions, some of the budget has been postponed from 2009 to 2010).
- Our Commission initiated some action in the domain of the "Rare Diseases Programs," on the premises that several governmental, European, and WHO programs are progressively implemented. It would be important for our community to take part, to defend the cause of the rare epileptic diseases, and to try to benefit from these multilevel actions. The IBE has been contacted on this subject.

Research:

Our Commission had to restrain all budgets dedicated to scientific meetings and tried to invest in actions of "European added value."

- A project on the mechanisms of SUDEP, "MORTEMUS" was supported financially. It is based on the collection of data across Europe on the largest possible number of cases of SUDEP or near-SUDEP that occurred in the EEG-video monitoring settings.
- Our Commission has undertaken a concerted action to promote epilepsy research at the European level. The key role of Asla Pitkanen should be particularly underlined. The goal is to identify the Epilepsy Research Priorities in Europe for

the coming decade. Research efforts on these priorities should guarantee that European epilepsy research stays and strengthens its position at the cutting edge of the world of epilepsy research, has a potential for decreasing the economic and social burden of epilepsy in Europe, and will lead to significant changes in diagnosis, treatment, and quality of life of patients with epilepsy. To achieve these ambitious goals, it was necessary to elaborate a representative opinion of the research areas that should be investigated. A workshop took place in Brussels, 17-18 January 2008, and a consensus document was elaborated, then published in *Epilepsia*, under the title: "Epilepsy research priorities for the next decade: a representative view of the European scientific community". (*Epilepsia* 2009; 50:571-583).

This document was distributed to all European Chapters with some recommendations on how to use it for lobbying purposes. (European deputies, EU national contact points, etc). It was also proposed to organize a follow-up meeting in 2010 that would update the research priorities. This could be done in collaboration with Günter Kramer in Zurich: this opportunity may bring some European added value to this Zurich meeting which theme is revolving around the "State of the Art in Epilepsy Research." The importance of giving a higher priority in the future to clinical research and social issues was emphasized by the CEA. The European Brain Council will utilize this document for elaborating its neuroscience program.

Budget:

Due to the global economical crisis, ILAE had to reduce its expenses. Following a letter circulated by the ILAE-EC, we revised our 2009 budget, and reduced it by a substantial percentage. Budgetary adjustments were made, trying to apply fairly similar percentages of reduction to every activity, but also taking into account the proximity in time of the event, its other financial support, and suggesting that some events can be postponed to 2010. The revised budget, with about 35% overall cut, was approved by the ILAE-EC in April 2009, with the hope that these CEA efforts will be appreciated.

Michel Baulac
Chair

COMMISSION ON LATIN AMERICAN AFFAIRS

List of Members:

Marco T Medina, Chair (Honduras)
Marcelo Devilat Barros, Secretary (Chile)
Salvador Gonzalez Pal, Treasurer (Cuba)
Patricia Campos (Peru)
Alejandro Scaramelli (Uruguay)
Henry B Stokes (Guatemala)
Elza Márcia Targas Yacubian (Brazil)
Esper Cavalheiro, Ex-Officio member (Brazil)

Aims:

1. To promote epilepsy education and research in the Latin American Region;
2. To coordinate academic activities among the ILAE Latin American Chapters;
3. To improve the health care of people with epilepsy in Latin America;
4. To provide and promote epilepsy education and research with excellence, quality, efficient and humanistic approach for medical and non-medical professionals in Latin America.

Commission Activities:

1. Latin American Epilepsy Academy (Academia Latino Americana de Epilepsia, ALADE)

On 12 February 2007 during the First Latin American Summer School on Epilepsy (LASSE) in São Paulo, an official meeting of the ILAE Commission on Latin American Affairs was carried out, with the participation of: Elza M Yacubian (Chair, ILAE Education Commission), Marcelo Devilat (Secretary), Henry Stokes, Alejandro Scaramelli, Marco T Medina (Chair, ILAE Commission on Latin American Affairs), Peter Wolf (ILAE President), Nico Moshé (ILAE Secretary), Esper Cavalheiro (LASSE Director), Fernando Cendes (ILAE Brazilian Chapter President) and Jaime Fandiño F (ILAE Colombian Chapter President).

During this meeting, the Latin American Epilepsy Academy (also known as ALADE: Academia Latino Americana de Epilepsia) was founded. The proposals from Brazil, Chile, Uruguay and Mexico were evaluated as well as the Rules and Regulations of the Asian Epilepsy Academy (ASEPA) and the European Academy of Epilepsy (EUREPA). Elza M Yacubian and Marco T Medina presented a Strategic Planning project for the ALADE.

ALADE Mission: To provide and promote epilepsy education and research with excellence, quality, efficient and humanistic approach for medical and non-medical professionals in Latin America.



Founding meeting: Nico Moshé, Alejandro Scaramelli, Henry Stokes, Esper Cavalheiro, Marco T Medina, Marcelo Devilat (standing, from left to right). Elza M Yacubian, Peter Wolf, Patricia Campos (seated, from left to right)

ALADE Vision: To be a Latin American Institution, a logistic Branch of the ILAE Latin American Commission and the ILAE Education Commission, established to promote and provide epilepsy education and research, aiming to improve the healthcare of people with epilepsy in the Region.

Goal: The goal of ALADE is to promote epilepsy education and research in the Latin American Region in order to improve health care of people with epilepsy.

ALADE Executive Committee: On 8 February 2008 during the Second Latin American Summer School on Epilepsy (LASSE II) in São Paulo, Brazil, the ALADE Executive Committee was elected by the ILAE Commission on Latin American Affairs. The members of the ALADE Executive Committee are: Elza M Yacubian, Patricia Campos, Silvia Kochen, Francisco Rubio Donnadieu, Alejandro Scaramelli, Esper Cavalheiro (Secretary) and Marco T Medina (President). They will serve from 2008 to 2011.

Legal Status: In February 2008, Esper Cavalheiro, Marco T Medina and Elza Yacubian signed the ALADE legal status document in São Paulo. ALADE has a permanent address in São Paulo Brazil as a non-profit organization. ALADE is the educational arm of the ILAE Commission on Latin American Affairs.

(continued on page 36)

COMMISSION ON LATIN AMERICAN AFFAIRS *(continued)*

ALADE LOGO:



Inaugural ALADE Activities: During the Vth Latin American Epilepsy Congress in Montevideo, Uruguay, 5-8 November 2008, successful inaugural academic ALADE activities took place. The following educational courses were organized: Neurobiology, Epilepsy Surgery, Electroencephalography, Video-EEG in Adults and Children and, Clinical Trials.

On 10 February 2009 during the 3rd Latin American Summer School on Epilepsy course, in São Paulo, Brazil, the members of the ALADE Executive Committee, Elza Yacubian, Silvia Kochen, Patricia Campos, Alejandro Scaramelli, Francisco Rubio Donnadiou, Esper Cavalheiro, and Marco T Medina discussed, evaluated and approved the ALADE Strategic Planning for 2009 to 2011. Dr Fulvio Alexandre Scorza was appointed as administrative manager.

2. Latin American Summer School on Epilepsy (LASSE)

During 2007 to 2009, three highly successful courses of the Latin American Summer School on Epilepsy (LASSE) were organized at the Santa Monica Hotel and Convention Center in Guarulhos, São Paulo, Brazil. The LASSE Director is Esper A Cavalheiro, and the members of the organizing committee were Elza Márcia Yacubian, Fulvio Alexandre Scorza, Lineu S Calderazzo Filho, Luiz Eugênio Mello, Américo Sakamoto, Alexandre Valotta da Silva, João Pereira Leite and Fernando Cendes.

1) The First Latin American Summer School on Epilepsy: "Epilepsy: translating basic knowledge into clinical applications," was organized from 4-14 February 2007;

2) The Second Latin American Summer School on Epilepsy: "Increasing knowledge and decreasing treatment gap," was organized from 7-17 February 2008;

3) The Third Latin American Summer School on Epilepsy: "Epileptogenesis in the developing brain: basis for treatment and prevention," was organized from 4-14 February 2009.

The LASSE courses have been a major success for many reasons including (a) the hotel location (far from appealing tourist attractions but with good services); (b) teacher's dedication, commitment and generosity; (c) the program that covered different aspects of basic and clinical epileptology allowing a closer interaction of

students from these two areas and (d) the open discussion with contributions of all teachers present at the conference room.

Future LASSE: From 28 January to 6 February 2010, the 4th Latin-American Summer School on Epilepsy (LASSE IV) will be devoted to the comprehension of the sequence of epilepsy-related events in an orderly and time-related manner. The School will emphasize the "timing" parameters at the molecular and the systemic levels essential to understand the physiopathological basis underlying seizures and the evolution of epilepsies. As events with time in biological organisms occur both on a continuous and a periodic basis, special attention will be devoted to the temporal regulation of biological events that could interfere with the seizure onset as well as with the life-time development of the epileptic syndromes. Special focus will be given to brain development, maturation and aging and to rhythms which govern the organism's life and their influence on epileptic mechanisms, such as the rest-activity and sleep cycles and other processes of circadian and seasonal regulation.

3. Latin American Epilepsy Congresses

a) The IV Latin American Epilepsy Congress was organized by ILAE and IBE through the ILAE Commission on Latin American Affairs and the IBE Latin American Affairs from 6-9 September 2006 in Guatemala City. The Co-Chairs of the Organizing International Committee, Henry Stokes and Martin Brodie and the members of the Scientific Organizing Committee, Juvenal Gutierrez and Carlos Acevedo, ensured that the scientific content was both of a high caliber and reflective of issues relative to the Latin American Region. More than 300 participants from all the Latin American countries attended the Congress. On 9 September 2006 the Latin American Epilepsy Day was also celebrated.

b) A major success was the Vth Latin American Congress on Epilepsy held in Montevideo, Uruguay, from 5-8 November 2008. The Organizing Committee included members from ILAE and IBE Latin American Commissions. Representatives from the Executive Committees of both ILAE and IBE, the Epilepsy Care Commission as well as members from the local organizing committee, worked in a close collaboration. The inaugural academic courses organized by ALADE were successfully carried out during this Congress. More than 600 participants from all the Latin American countries attended the Congress.

4. Latin American Epilepsy Surgery Subcommittee

The ILAE Commission on Latin American Affairs with the approval of the ILAE President, Peter Wolf, appointed a new Latin American Epilepsy Surgery sub-committee. The members of this sub-committee are:

(continued on page 37)

COMMISSION ON LATIN AMERICAN AFFAIRS *(continued)*

Americo Sakamoto (Chair), Manuel Campos (Secretary), Mario Alonso, Jaime Fandiño, Juan Bulacio and a member from Central America (Costa Rica).

The term of this sub-committee will be the same as the ILAE Commission on Latin American Affairs. The main goals of this sub-committee are to improve the epilepsy surgery gap in Latin America, promote education and research on epilepsy surgery and, work closely with ALADE. This sub-committee is working also with other ILAE Commissions: Therapeutics (Dr Gary Mathern), North America (Dr Samuel Wiebe) and Epilepsy Care, mainly on the epilepsy surgery gap project and certification pilot project.

5. WHO/ILAE/IBE Global Campaign Against Epilepsy

a) Demonstration project on epilepsy in Brazil: A successful demonstration project was carried out (Li, L M et al. *Arq Neuropsiquiatr* 2007). They performed a door-to-door epidemiological survey in three areas to assess the prevalence of epilepsy and its treatment gap. They surveyed a sample of 598 primary healthcare workers from different regions of Brazil to assess their perceptions of the management of people with epilepsy in the primary care setting. The lifetime prevalence of epilepsy was 9.2/1,000 people and the estimated prevalence of active epilepsy was 5.4/1,000 people. Thirty-eight percent of patients with active epilepsy were on inadequate treatment, including 19 percent who were taking no medication. Based on this demonstration project a program was started: 1) establishing referral network, 2) continuous provision of AEDs, 3) close monitoring of epilepsy management via the notification system (Sistema de Informação da Atenção Básica – SIAB) and 4) continuous education of health professionals.

b) Global Campaign and WHO/PAHO Central American Regional Meeting Representatives from the Pan American Health Organization/World Health Organization, (Victor Aparicio, Jorge Rodriguez, Jose Bertolote) ILAE (Marco T Medina, Henry Stokes) and IBE (Carlos Acevedo) and Central America, Cuba, Dominican Republic and Mexico representatives had a meeting in Tegucigalpa, Honduras on 21-23 August 2008 to promote the Epilepsy Global Campaign in the region. Dr Acevedo presented a Latin America Epilepsy Report and Dr Bertolote the Spanish translation of the *Neurological Disorders: Public Health Challenges* book. During this meeting a pilot demonstration project was proposed in Honduras and a Regional Consensus on epilepsy was achieved

6. Education Project with The North American Commission (joint report from the North American and Latin American Commissions)

Members: Sheryl Haut (Leader), Jean Gotman, Nizam Ahmed, Juan Ochoa, José Cavazos, Marco T Medina

(Latin American Commission), Elza Yakubian (Education Commission).

The North American and the Latin American Commissions of the ILAE have joined forces in their commitment to improve the quality of epilepsy care in Latin America. The primary vehicle used is improvement in the transfer of knowledge. Accordingly, the group has designed and is beginning to implement a three-level plan:

Level One: Selected epileptologists from the North American Region, knowledgeable in Spanish or Portuguese have visited medical centers in Latin America for one to two weeks. They were active in regional epilepsy meetings and spending time in epilepsy centers, teaching clinically and didactically, as well as participating in clinical discussions. The intent is to reach as many healthcare providers as possible. Under the leadership of Dr J Cavazos, this component of the educational initiative has received funds from an unrestricted grant from the USA pharmaceutical industry.

Level Two: Relationships will be established between North American and Latin American Commissions for exchange of information, primarily through electronic means, including video conferencing and particularly Web-based exchanges and telephone conferences. This could include clinical aspects, training issues, and other case-based discussions.

Level Three: A long-term relationship will be established between North American and Latin American centers, possibly spanning from one to three years, involving training at the North American center of a number of staff and personnel from the trainee center in Latin America.

The Latin American Commission (through ALADE) is participating actively throughout the process, and providing feedback in terms of results and direction of these educational initiatives. The first level already started in the following countries: Peru, Panama, Costa Rica, Ecuador and Mexico. Funds for the Visiting Professorships from 2008 to 2012 have been received and are in an account at the AES. Overall, the programs have been very successful.

7. Island of Hispaniola (Haiti) Project (joint report from the North American and Latin American Commissions)

Members: Lionel Carmant (leader, Canada), Marco Medina (Latin American Commission), Diogenes Santos-Villorio (Dominican Republic), Michel Baldy Mouliner (EUREPA), Alex Elie (Haiti), and Marcel Severe (Haiti).

(continued on page 38)

COMMISSION ON LATIN AMERICAN AFFAIRS *(continued)*

The thrust of this project was to develop epilepsy clinics/centers in Haiti. Initial groundwork has uncovered a dramatic lack of epilepsy resources and expertise in epilepsy. The initial activities included providing training for technologists and epilepsy nurses from Haiti at a Dominican Republic center. Importantly, the Canadian League Against Epilepsy has been actively involved in this project. External resources being sought involve groups from the USA, Canada, and also a project in collaboration with Dominican region to address the problem of neurocysticercosis. On 4 June 2008, la Clinique d'épilepsie de Port-au-Prince was up and running. The Task Force has identified the most significant needs of the Island: 1) Provide access to proper epilepsy care to the Haitian population, 2) Eradication of neurocysticercosis from the Island of Hispaniola and, 3) Support the development of an Epilepsy Surgery program.

8. *Epilepsia en Español*

The Editor of *Epilepsia en Español* is Prof Natalio Fejerman. This important activity was started in 2006 with economic support from the ILAE. During 2008 the distribution of *Epilepsia en Español* was improved significantly. Dr Fejerman received favorable comments from many colleagues from the Chapters of Latin America and Spain. Marco T Medina and Elza Márcia Yacubian were included as Co-Editors. An electronic version will be available in the near future, with the support of the pharmaceutical industry.

9. Educational Symposiums

a) Epilepsy Educational Symposium supported by the ILAE Latin American Commission during the Pan-American Neurology Congress, Dominican Republic. During the Pan-American Neurology Congress on 7-13 October 2007, the Latin American Commission, the North American Commission and the Dominican Republic Chapter organized an Educational Epilepsy Course (on 10 October 2007), with the participation of: Samuel Wiebe (North American Commission, Canada) Lionel Carmant (Canadian ILAE Chapter), Henry Stokes (Latin American Commission, Guatemala), Salvador Gonzalez-Pal (Latin American Chapter, Cuba), Marco T Medina (Latin American Commission), Diogenes Santos Vilorio, Jose Cabrera and Rosario Gomez (ILAE Dominican Republic Chapter), Franz Chaves-Sell (ILAE Costa Rican Chapter), Antonio V. Delgado-Escueta and Diana Kraemer (USA).

b) During the International Epilepsy Congress, in Singapore on 10 July 2007 the IBE and the ILAE Latin American Commission organized a session on

Complementary and Alternative Therapy for Epilepsy with the participation of Dr Lilia Nunez (Mexico), Alicia Bogacz (Uruguay), Franz Chaves-Sell (Costa Rica) and Marco T Medina (Honduras).

Accomplishments:

1. The Latin American Academy of Epilepsy (Academia Latino Americana de Epilepsia, ALADE), founded on 12 February 2007, in São Paulo Brazil;
2. Latin American Summer School on Epilepsy (LASSE);
3. Successful Latin American Epilepsy Congresses in Guatemala (2006) and Montevideo (2008);
4. Creation of the Epilepsy Surgery sub-commission;
5. Successful Global Campaign regional activities;
6. Establishing a collaborative work with the ILAE North American Commission.

Recommendations for Future Work:

- 1) Continuous support to the Latin American Epilepsy Academy (ALADE) and the regional educational activities (i.e., Mesoamerica and Caribbean, Andean, etc.);
- 2) Support to LASSE as an important educational activity;
- 3) Improve basic and epidemiological research;
- 4) Improve the epilepsy care in Latin America (i.e., neurocysticercosis project, epilepsy surgery gap and treatment gap);
- 5) Support to the Latin American Congresses. The Region needs to improve the financial support for the long-term sustainability.

Summary:

Based on this teamwork, the ILAE Commission on Latin America Affairs took a big step forward, becoming a mature region: with the foundation of the Latin American Academy of Epilepsy (ALADE); periodical and successful regional epilepsy Congresses; the successful Latin American Summer School on Epilepsy (LASSE); establishment of new sub-commissions, like the Epilepsy Surgery Sub-commission, successful Global Campaign regional activities and, the collaboration with the ILAE North American Commission. We still have several challenges in order to improve epilepsy healthcare, research and education in our Region.

Prof Marco T Medina
Chair

COMMISSION OF THE NORTH AMERICAN REGION (NAC)

I. General Aspects of the NAC

The current North American Regional Commission (NAC) was constituted in 2006, comprising English-speaking North American Chapters of Canada, the United States of America, and the English-speaking Caribbean (represented by Jamaica). The Mexican Chapter, although geographically in North America, is a member of the Latin American Regional Commission. The Commission was composed of the following eight voting members and two non-voting members:

Voting Members:

Sam Wiebe, Chair (Canada)
Sheryl Haut, Secretary (USA)
Lionel Carmant, Treasurer (Canada)
Amza Ali, Jamaica (Caribbean)
Bob Fisher (USA)
Jean Gotman (Canada)
Jack Pellock (USA)
Jeff Noebels (USA, AES International Affairs Committee)
AES President (USA, Ex-Officio)
Nico Moshé (ILAE Secretary General, Ex-Officio)

Invitees:

Ms Sue Berry, American Epilepsy Society (AES)
Executive Director
Dr Marco Tulio Medina, Chair, Latin American Commission
Members of ILAE Executive Committee
Members of Task Forces

II. Goals and Operations

The NAC held quarterly teleconferences and annual face-to-face meetings at the AES. Reports were provided annually to the ILAE Executive Committee, in accordance with ILAE stipulations for Regional Commissions, and annual updates were provided to each of the three constituent Chapters (Canada, Jamaica, USA).

The Commission's overall goal was to improve the delivery of epilepsy care throughout the Americas and the Caribbean.

III. Task Forces

To achieve its goals, the NAC constituted four Task Forces:

- A. Task Force on Education
- B. Task Force on Disparities in Epilepsy Care
- C. Task Force for Caribbean Development (English-speaking Caribbean)
- D. Task Force for Island of Hispaniola Development (Haiti and Dominican Republic)

All Task Forces established agendas with tangible deliverables and were encouraged to form work groups that included non-Commission individuals as needed to achieve their goals. The agendas of all Task Forces

were discussed and approved by the NAC and the budget was assembled and submitted in accordance with these strategies. Task Forces held regular telephone conferences throughout the year, and met face-to-face once a year at AES meetings. Progress reports were given to the NAC members at each of their meetings, and discussion of the reports informed further actions. By the nature of its goals and geography, the NAC and its Task Forces worked closely with other ILAE Commissions and Chapters, in particular with the Latin American Regional Commission, the ILAE Therapeutics Commission (Task Force for Epilepsy Surgery), and the Caribbean Chapters.

Each Task Force's mission, composition and progress report are summarized below:

Task Force on Education

Members: Sheryl Haut (Leader), Jean Gotman (Canada), Nizam Ahmed (Canada), Juan Ochoa (USA), José Cavazos (USA), Jorge Vidaurre (USA), Arthur Grant (USA), Carly Mann (USA), Marco Medina (Chair, Latin American Commission), Elza Yakubian (Chair, Education Commission).

The mission of the Task Force on Education of the NAC has been to promote and improve epilepsy education and care in North and Latin American Regions. The Task Force decided that the best approach to achieve its goals was to develop long-lasting academic and clinical relationships between Latin American (LA) and North American (NA) centers. This could be best accomplished by establishing partnerships between LA and NA groups or centers. Accordingly, the Task Force developed and supported collaborations between epilepsy centers in NA, LA and the Caribbean, utilizing three methods implemented in three phases: Phase 1: Pairing of centers and visiting professorships. Phase 2: Telemedicine-based partnerships to provide continuity. Phase 3: Extended mentorships consisting of rotations or visits of specific personnel from LA centers to NA centers. With significant additional support from UCB through an educational grant obtained by José Cavazos, Phase 1 of the program was launched in 2008. A standard application and matching process was developed, and a call for proposals was sent out to AES members and publicized through the Latin American Commission. Applications were reviewed by the Task Force and were selected based on specific criteria, including merit of the planned curriculum, experience of the applicant, and viability of long-term collaboration.

- i. Phase 1: Six visiting professorships were awarded in the first year, and four in the second. Thus far, visits have taken place between faculty of North American epilepsy centers, and centers in the following countries: Ecuador, Panama, Costa Rica,

(continued on page 40)

COMMISSION OF THE NORTH AMERICAN REGION (NAC) *(continued)*

Mexico, Peru, Jamaica, and Colombia. During these visits, the visiting faculty gave lectures, conferences and rounds to a variety of healthcare providers, and met with hospital, local and government officials to promote the development of epilepsy centers and/or epilepsy surgery. These visits were felt to be very successful based on feedback from both the visiting faculty and the receiving centers. Each visiting faculty submitted a report of the visit, which was reviewed by the Task Force. Specifics of these professorships are as follows:

1. David Clarke, MD of the University of Tennessee HSC at Memphis, has partnered with the Jamaican Chapter of the ILAE and has extended his participation to the English-speaking countries of the Caribbean and also the Dutch Antilles. He also received significant matching funds from the Le Bonheur's Children Medical Center in Memphis to develop epilepsy care in the region. Dennis and Susan Spencer from Yale University have also participated in this collaboration with the Caribbean;
 2. Patricio S Espinoza, MD of Brigham & Women's Hospital, Harvard Medical School, is engaged in partnership with Quito, Ecuador, at the Universidad San Francisco de Quito, and has begun teleconferences with six sites from different regions within Ecuador. Pictures posted <http://picasaweb.google.com/PS.Espinosa/IVSeminariointernacionalEnNeurociencias2008?authkey=lm0QT95yXOA>;
 3. Jorge Burneo, MD of the University of Western Ontario, Canada, is engaged in a partnership in Lima, Peru and participated in a series of events with the Peruvian Chapter of the ILAE. This has involved an extremely promising initiative on Neurocysticercosis and epilepsy;
 4. David Labiner, MD of the University of Arizona, partnered with neurologists in Costa Rica quite successfully, has established teleconferencing, and plans for return visits are in place;
 5. Greg Krauss, MD of John Hopkins University, has established a successful partnership with the group in Panama;
 6. José Cavazos, MD of the University of Texas Health Science Center has partnered with the Hospital Infantil de Mexico, which is the main pediatric hospital in Mexico City;
 7. Juan Ochoa, MD of the University of Florida has partnered with the group in Cartagena, Colombia and plans are underway to expand to other centers in Colombia.
- ii. Phase 2: This phase began at the conclusion of each visiting professorship, with a telemedicine partnership established between the visiting faculty and the Latin American or Caribbean site. These partnerships are ongoing. Admittedly, this is a challenging aspect of the initiative and one that requires not only experience of Task Force members, but also perseverance and a level of maturity in the partnership that can allow participants to benefit from this method.
 - iii. Phase 3: This is contemplated as a later stage that will emerge from a maturing relationship between centers and which will be required for development of targeted epilepsy expertise in LA centers. In the planned Phase 3 of the project, repeat visits by North American faculty will take place, and members of the Latin American centers may visit the North American centers to receive further training.

Task Force on Disparities in Epilepsy Care:

Members: Jorge Burneo (Leader), Sam Wiebe (Canada), Allan Hauser (USA), David Thurman (USA, Centers for Disease Control), Margaret Jacobs (USA, NIH), Karen Parko (USA, Public Health Service), Charles Begley (USA), Nathalie Jetté (Canada), Jack Pellock (USA).

The purpose of the Task Force was to frame the issues regarding disparities in epilepsy in the North American region (including the English-speaking Caribbean), to include the development of an agenda for research, research capacity building, and outreach. The specific tasks were to inform the NAC regarding the occurrence and extent of disparities in epilepsy, the nature of the disparities (points of intervention), and the array of potential interventions. The Task Force conducted a systematic review to evaluate the current knowledge about the issue of disparities in the Region, and to identify potential interventions.

The systematic review was completed, and presented as a platform presentation during the last American Epilepsy Society meeting in Seattle. This resulted in a manuscript that was submitted to *Epilepsia* after approval by the Commission and the Executive Committee of the ILAE, and has been subsequently accepted for publication. The primary outcome of this systematic review of the current state of knowledge was a set of recommendations regarding the next steps to address the identified disparities. Five areas were identified:

- i. Epidemiology of epilepsy. Although the research is relatively sparse, minority populations have a higher frequency of epilepsy than whites. However, minority populations other than African Americans have not been studied to any extent. The reasons for the

(continued on page 41)

COMMISSION OF THE NORTH AMERICAN REGION (NAC) *(continued)*

racial/ethnic differences in the occurrence of epilepsy remain to be identified. There is no epidemiological information about epilepsy in the English-speaking Caribbean;

- ii. Knowledge and attitudes about epilepsy. Due to the absence of comparative studies, it is impossible to know how much and in what dimensions knowledge of or attitudes toward epilepsy differ from feelings concerning other chronic disorders. Community attitudes appear to have improved over time, and education can be a positive factor. Specific ethno-cultural beliefs would need to be addressed. The lack of knowledge of persons with epilepsy (PWE) themselves is of concern;
- iii. Disparities in employment and education. There also appear to be discrepancies between different studies in terms of employment status in patients with epilepsy when compared with those without it. However, there appears to be a lower educational level attained in those with epilepsy compared to the general population. More studies are needed to clarify these discrepancies;
- iv. Access to medical and surgical care. While there is a suggestion that African Americans have higher rates of hospitalizations and emergency room (ER) visits, and lower rates of epilepsy surgery, because insurance status and low socioeconomic status (SES) also had an association in some of the studies, it is not clear whether racial/ethnic factors causally relate to rates of care. In Canada, aboriginals with epilepsy were less likely to see a neurologist and more likely to visit the ER, a finding which could not be explained by lower SES or rural residence. Other disparities in population-based studies include more ER and fewer counseling visits in people living in less densely populated and remote areas, and more barriers to care in those living in urban areas. Women and children are more likely to see a neurologist than men and adults, respectively. In two studies with different methods, cultures, and populations, poor compliance with AEDs was associated with external factors such as lower income, insufficient insurance and poor relationship with treating clinicians, as well as with internal factors such as not having regular responsibilities. Clinical, demographic and cognitive factors were not associated with compliance with medication. Disparities in mental health care have been documented in people with epilepsy. Lower rates of mental health treatment in children with epilepsy are associated with older age, lower parental education, higher verbal IQ, and AED polytherapy;
- v. Outcomes following medical and surgical treatment. There is little research on the role of SES, gender, race/ethnicity, age, education, and comorbidities in relation to outcomes following medical treatment for

people with epilepsy. The published data are not sufficient to reach conclusions regarding the relationships between these factors. Information is scarce regarding possible disparities in epilepsy surgery outcomes. More studies, particularly with a large sample size, are needed.

Task Force for Caribbean Development

Members: Amza Ali (leader, Jamaica), Robert Fisher (USA), Jeff Noebels (USA), Sharon Whiting (Canada, formerly Jamaica), David Clarke (US formerly from Antigua), Neil Cruz (US Virgin Islands).

The mission of this Task Force was to improve knowledge of epilepsy in all categories of healthcare workers in Jamaica and in the rest of the English-speaking Caribbean (ESC), and to advance epilepsy care in the ESC. Outlined below is a description of the initiatives, methods and results:

- i. Quarterly JLAE educational meetings: These events are attended by a wide variety of interested medical and other healthcare workers. Speakers have included local practitioners but the keynote speaker has often been a well-known epileptologist from North America or Europe;
- ii. Biennial North American Regional Caribbean Congresses: The inaugural Congress was held in Montego Bay in May 2008. The event was a truly collaborative endeavor involving the North American Commission of the International League Against Epilepsy (ILAE), the Jamaican League Against Epilepsy (JLAE), the Jamaican Epilepsy Association, the American Epilepsy Society (AES), and The Canadian League Against Epilepsy (CLAE), as well as the international corporations Novartis and Bank of Nova Scotia. The high profile of the Congress was evident by the participation of regional dignitaries and of regional and international speakers. During the official opening ceremony, the Honorable Rudyard Spencer, Minister of Health of Jamaica, eloquently acknowledged the difficulties and stigma facing persons with epilepsy, and pledged his commitment to work with the JLAE to improve the care and quality of life of people with epilepsy in Jamaica. The success of the First North American Regional Caribbean Congress of Epilepsy allows us to envisage an era of new initiatives and collaborations that will lead to better care and quality of life of patients with epilepsy in this Region. The Second North American Regional Caribbean Congress, will take place in Curacao in 2010;
- iii. Monthly Case Conferences and Pre-surgical evaluation group: These monthly events were started in late 2008 and led to the formation of the pre-surgical evaluation group. Initially the group

(continued on page 42)

COMMISSION OF THE NORTH AMERICAN REGION (NAC) *(continued)*

was composed of five adult and pediatric neurologists as well as a psychiatrist; more recently the core membership expanded to include a neuropsychologist, neurosurgeon and a neuroradiologist. This new group, based at the University and co-chaired by Dr Amza Ali and by Professor Ivor Crandon, Head of the Department of Neurosurgery, are dynamic and spirited events, with the intention of arriving at a consensus in the management of difficult cases. Difficult cases evaluated and managed to the fullest possibilities locally have been sent to Dr Dave Clarke at the University of Tennessee for further evaluation and investigation, particularly involving high quality imaging and magnetoencephalography. This has been made possible by the North American Commission's selection of Dr Clarke as Visiting Professor to the Caribbean Region. He has already made three trips to the Caribbean, Jamaica initially and subsequently Trinidad. The group further benefited from the recent visit to Jamaica of Professors Dennis and Susan Spencer in April, also sponsored by the North American Regional Commission as part of the Visiting Professorship program;

- iv. Expansion of the JLAE to include the wider English-speaking Caribbean territories (ESC): When the NAC was formed it was proposed that the JLAE would be more effective if its membership was expanded to include interested healthcare workers from the rest of the English-speaking Caribbean, based on the existing political affiliation that already exists in the region, i.e., Caricom (Caribbean Community). This concept was discussed with the ILAE Executive Committee including Peter Wolf and Solomon Moshé, and favorably viewed. Consequently in 2006 this was supported by Dr Henry Fraser, Dean of the Faculty of Medicine in Barbados, and 15 physicians including neurologists, internists, psychiatrists and pediatricians joined as associate members;
- v. Interaction with the Jamaican Epilepsy Association (JEA). This is the local Chapter of the International Bureau for Epilepsy (IBE). This organization has been a great success and since its establishment in 2002 has worked closely with the JLAE to achieve many common goals. The Task Force's emphasis has been on strengthening collaboration, which is a model that could very well work in other countries and regions. Together we have focused on educational initiatives especially the hosting of conferences, smaller gatherings with patients and the development of educational pamphlets and posters for free distribution as well as a children's book for epilepsy, *Way to go Flash!* Perhaps the most significant joint achievement was fundraising for and establishing the only Video-EEG facility in

the ESC in 2004. This unit has evaluated approximately 100 patients so far, contributing greatly to more accurate diagnosis and management. This collaboration will be essential as the JLAE with its North American partnerships established through the NAC, moves on to offer epilepsy surgery in the region.

Task Force for Island of Hispaniola Development (Haiti and Dominican Republic):

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

The mission of the Task Force was threefold: i) to bring epilepsy care to Haiti; ii) to open an Epilepsy Surgery Center in Santo Domingo; and iii) to reduce the incidence of neurocysticercosis and epilepsy related to neurocysticercosis on the Island.

- i. Epilepsy clinic in Haiti: On 4 June 2008, la Clinique d'épilepsie de Port-Au-Prince, an outreach initiative of the NAC opened its doors to patients. Haiti, the French-speaking half of the island of Hispaniola, had no neurologist or trained



Dr. Sévère and a patient at the clinic

electroencephalographers. There were only two conventional EEG machines (one of which is 8-channels), to serve a population of 8 million, and what recordings were done were reviewed outside of the country. At its first business meeting in 2006, the NAC identified Haiti as a region with some of the most urgent needs for improved epilepsy care in the world. This successful ILAE-led development is a true collaborative effort involving centers and agencies in Canada, the USA, and the generous support of neighboring Dominican Republic. Training for a Haitian EEG technologist and a

(continued on page 43)

COMMISSION OF THE NORTH AMERICAN REGION (NAC) *(continued)*

Haitian Epilepsy nurse took place in the Dominican Republic under the supervision of Diogenes Santos Viloría for six months. Simultaneously, Dr Marcel Sévère, a young pediatrician from Haiti obtained EEG training for three months in Montreal under the supervision of Dr Lionel Carmant. Subsequently, thanks to a generous gift of a used EEG machine from Stellate EEG Systems Inc., Dr Carmant and an EEG technologist from Montreal travelled to Port-Au-Prince to help install the EEG machine in early June 2008. The team stayed for a week, seeing patients and performing EEGs with the local team, led by Dr Alix Elie a neurosurgeon who is the national epilepsy specialist. Dr Elie is now volunteering to be in charge of the clinic, and Dr Sévère reads all EEGs, e-mailing Dr Carmant difficult tracings. This was accomplished with \$6,000 funding from the ILAE. Dr Carmant then secured matching funds from the Canadian Neurological Sciences Foundation and submitted an application for a \$10,000 grant to the Savoy

Foundation for Epilepsy in Quebec, Canada. Dr Farah Lubin assisted in seeking funds for the clinic. The epilepsy clinic in Port-Au-Prince Haiti has developed rapidly. Since June 2008, more than 500 patients have been evaluated at the clinic, some of these patients travel from rural areas to receive epilepsy care. The Task Force will be providing ongoing support via quarterly visiting professorships from North American Commission members. Enduring resources require local educational efforts. In this regard, progress is being made to include teaching about epilepsy in the neurology curriculum at the Faculty of Medicine of the National University (Université d'Etat d'Haiti). The latter will be done in collaboration with the Association of Haitian Physicians (AMHE);

- ii. Neurosurgery center in Santo Domingo: This endeavor has relied mainly on the efforts of Drs Rivera and Santos Viloría. Dr Rivera has supervised the construction of a neurosurgical unit in Santo Domingo. Dr Santos Viloría came to Montreal to get a refresher in video-EEG and corticography recording. Dr Ferreira from Florida has offered video-EEG equipment as well as help to review recordings and perform investigation. In addition, Dr Selim Benbadis from Florida has put together a professorship program that will help implement this epilepsy surgery center. This part of the project has been done with no funding, but the professorship is associated with a \$5,000 grant from the Educational Task Force to support travel between the centers;
- iii. Neurocysticercosis Project: We have begun to assess the presence of neurocysticercosis in the endemic region of the island which encompasses the border

between Haiti and the Dominican Republic. The project was developed in consultation with NIH-supported and renowned epidemiologist Dr Hugo Garcia from Peru. We have started on the Dominican side of the region. A preliminary census performed by Drs Santos Viloría and Rivera suggest a high incidence of epilepsy in this region. With \$20,000 of funding from the ILAE NAC, we will perform the screening of 100+ patients with epilepsy per year for two years to assess the frequency of neurocysticercosis in this region. This approach has been used successfully by Dr Garcia and will help us obtain funding to perform a similar estimate on the Haitian side and to begin a large scale prevention campaign to reduce the prevalence of the disorder. To enhance recruitment, we will reach out to influential individuals in the communities, such as the local physicians and priests.

IV. North American Regional Epilepsy Congresses

Starting in 2006 in San Diego, the American Epilepsy Society (AES) decided to designate every other Annual Meeting as the North American Region Epilepsy Congress. In the year of the North American Regional Congress, the AES meeting advertisement and logos bear the title of North American Region Epilepsy Congress, and the logos of the Canadian, Jamaican and USA ILAE Chapters. With generous support from the American Epilepsy Society (AES), the NAC has implemented a North American Regional Symposium which takes place every other year during the North American Region Epilepsy Congress. Two such symposia have taken place:

- a. First North American Regional Epilepsy Symposium: This inaugural symposium took place during the 60th meeting of the AES in San Diego. It was devoted to introductory presentations by ILAE Executive Committee members and newly appointed NAC Commission members, describing the goals and future activities of the NAC and the ILAE Global Campaign Against Epilepsy.
- b. Second North American Regional Epilepsy Symposium: Seattle, Washington, hosted the second North American Regional Epilepsy Congress during the AES 2008 Annual Meeting. The keynote event was entitled "Epilepsy and the World: Neuroinfections," and took place on Monday, 8 December, from 7:00 p.m. to 9:30 p.m. The symposium attracted extensive media coverage because of its scope and participants. The objectives of the symposium were: A) To obtain up-to-date evidence-based information about the mechanisms of epileptogenesis in neuro-infections. B) To review the most common neuro-infections producing epilepsy worldwide. C) To review the challenges of managing epilepsy in the context of anti-infectious

(continued on page 44)

COMMISSION OF THE NORTH AMERICAN REGION (NAC) *(continued)*

agents. D) To obtain an overall view of the impact of neuro-infections on epilepsy. The program was delivered through presentations from Drs Shi Chuo Li (China, epidemiology), Hugo Garcia (Peru, Neurocysticercosis), Angelina Kakooza (Uganda, HIV), Charles Newton (UK/Kenya, Malaria), and William Theodore (USA, Epileptogenesis of Neuroinfections). The program is available at <http://www.aesnet.org/go/meetings-and-events/annual-meeting>.

V. Interaction with Latin American Regional Commission

The NAC shares important common links with the LA Commission. Strengthening this collaboration remains a crucial aspect of NAC activities. During this term, the NAC Chair participated in various activities of the LA Commission, including their Regional Congress and LA Chapter convention. Similarly, the LA Commission Chair was a member of the NAC.

VI. Challenges

Challenges to the mission of the NAC and its Task Forces have been many. Lack of funding for continuation or expansion of goals and projects remains one of the biggest challenges faced by all the Task Forces. Other challenges included:

- a. Maintaining and strengthening relations with the Latin American Regional Commission.
- b. Identification of appropriate Latin American centers for the education initiative.
- c. Ongoing maintenance of the epilepsy clinic in Haiti, including technical problems with the EEG machine.
- d. Resistance of many senior physicians to changing long-held views about capabilities of persons with epilepsy in the Caribbean, in particular related to occupation and the right to hold a driving license.
- e. Slow recruitment of physicians across the Caribbean in the activities of the JLAE. Over the past two years several attempts have been made to have Trinidadian physicians, like our Barbadian colleagues, become engaged in activities of the JLAE. Despite interest this has not yet happened.

VII. Future Directions

Education Task Force:

The educational initiative is a long-term project. It is anticipated that the first phase of the program will run for at least five years in total, with four to five new partnerships established per year. Each visit is anticipated to result in an ongoing partnership supported by the ILAE. For the immediate future, the program will continue in 2009, with another four

visiting professorships awarded (mostly with UCB funding). The second and in particular the third phase will only be successful if they are maintained over the long term.

The Task Force plans to publish the results of the program to date. The editors of *Epilepsia* have been approached, and a report for the Grey Matters section is in process. We feel that methods and results of this program are applicable to many other regions of the world that are underserved in terms of epilepsy education and care. We are exploring the means to present this program as a pilot program to other ILAE Commissions.

Disparities Task Force:

Potential projects include:

1. Epidemiology of epilepsy in the English-speaking Caribbean;
2. Epidemiology of epilepsy in aboriginal communities of North America;
3. Evaluation of treatment gap in North America. Members of the group have agreed to continue to pursue this important topic. Planned requests for funding include contacting NIH, EFA, and possibly CIHR;
4. Work completed by the Task Force is being used as a model by the ILAE Commission on Epilepsy Care to implement a project assessing the determinants of disparities in epilepsy care in two developing countries on opposite sides of the world, India and Brazil.

Caribbean Task Force:

We plan to widen the membership of the JLAE to create the Epilepsy Society of the Caribbean (ESC). Efforts will be made this year to get interested Trinidadian physicians to join individually as they have not been able to organize themselves in a group. We also hope to attract other physicians from the other nearby Eastern Caribbean islands, including Dominica, St Kitts, Grenada and St Lucia and to invite them to join our efforts. We intend to approach the Bahamas to have them join the Society and also to have the English-speaking Dutch-affiliated Caribbean islands of Aruba, Bonaire and Curacao join as well. The overall objective of this wide membership is the creation of a regional referral system for the evaluation and management of more difficult cases within the Region, thereby developing local expertise and reserving the referral to North America for the most difficult cases.

After a visit by Drs Dennis and Susan Spencer, it is our plan to continue to develop the Epilepsy Surgery Program. Professor Ivor Crandon, Head of

(continued on page 45)

COMMISSION OF THE NORTH AMERICAN REGION (NAC) *(continued)*

Neurosurgery at the University of the West Indies, has committed to working on this initiative. We hope to set up teleconferencing between Yale, the University of Tennessee and the University of the West Indies, Mona (Jamaica) campus this year. Dr Dennis Spencer has offered to visit in the future to perform epilepsy surgery and provide direct training in these techniques.

We hope to set up a Task Force for the next and all future Biennial North American Regional Caribbean Congresses. This Task Force can also include physicians from islands other than Jamaica. Discussion is ongoing with the current President of the Southern Clinical Neurological Society of the US (SCNS), Basim Uthman MD, as it is planned to have a joint meeting with that organization in January 2010 in Curacao.

The Principal of the Jamaica campus of the University of the West Indies and the Dean of the Faculty of Medical Sciences (Jamaica) have expressed interest in this initiative to improve epilepsy care across the region. We are also grateful to have obtained the support of the Vice-Chancellor, Professor Nigel Harris, who launched the pre-surgical evaluation group in March 2009. His support will greatly facilitate the regionalization effort that will foster new research in the area.

Hispaniola Task Force:

In addition to the objectives we had set from the onset, we now want to provide Haiti with a neurology curriculum at the National University Medical School. This will be performed by the two members of our Task Force of Haitian origin and by two stroke specialists also of Haitian origin, Drs Stanley Elysée (Quebec City) and Jean-Robert Desrouleaux (New York). We are preparing the documents to apply for an ILAE Chapter for Haiti. The upcoming visit by Dr Benbadis to Santo Domingo is eagerly anticipated, in the efforts to improve epilepsy care in this region.

Samuel Wiebe, MD, FRCPC
Chair, Commission of the North American Region

Sheryl Haut, MD
Secretary, Commission of the North American Region



Topic-Oriented Commissions

COMMISSION ON CLASSIFICATION AND TERMINOLOGY

List of Members:

Anne T Berg, Chair (USA)
Samuel F Berkovic (Australia)
Jeffrey Buchhalter (USA)
Jerome Engel Jr (USA)
Tracy A Glauser (USA)
Douglas Nordli Jr (USA)
Perrine Plouin (France)
Philippe Ryvlin (France)
Ingrid E Scheffer (Australia)
Walter van Emde Boas (Netherlands)
Jacqueline French, Therapeutics Liaison (USA)
J Helen Cross, Pediatrics Liaison (UK)
Gary W Mathern, Therapeutics Liaison (USA)
Ruth Ottman, Genetics Liaison (USA)
Peter Wolf, MD, EC President (Denmark)
Solomon L Moshé, MD, EC Secretary-General (USA)
Martin Brodie, EC Treasurer (Scotland)

Aims:

(1) To propose revisions to the current terminology and concepts used in the classification of epilepsy and seizure types; (2) To explore and propose a future approach to organizing information about epilepsy; and (3) To explore and propose future methods that will serve as an objective foundation for classification in the future.

Commission Activities:

The Commission on Classification and Terminology has held yearly meetings at the AES as well as at the Singapore ICE (2007), and a dedicated two-day meeting in Paris, France (June 2008). Following the Commission Chairs' meeting in Brussels (October 2007), liaisons from Pediatrics, Therapeutics, and Genetics were invited to join all Commission meetings to provide input into our deliberations. Commission members have participated in sessions and symposia on or relevant to classification including at the Singapore IEC in 2007, the Asian Oceanian Epilepsy Congress (Regional Congress) in Xiamen, China 2008, and the Seattle AES in 2008. In addition, several Commission members took part in the Monreale Workshop (Sicily, April 2008) the proceedings of which are now available in *Epilepsia*. A presentation of the Commission's recommendation will be made in a parallel session at the Budapest IEC. In preparation for the Budapest meeting, we have posted both a summary and a full draft of the report on the ILAE Web site, alerted Chapter Presidents of its availability, and had a link created to it on the IEC Web site.

Accomplishments:

The Classification section on the ILAE Web site was updated. Specific changes included providing a summary of some of the intended revisions that were being considered, a translation between the 1981 seizure classification scheme and the more complex

one recommended in 2006, and a listing (with links to PDF when available) of relevant ILAE Commission documents as both a reference source and a general resource in following the formal history of classification in epilepsy. This will be further updated in the near future.

Through the various presentations and participation in workshops, the Commission members have communicated key aspects of the changes we are attempting to effect in the methods and philosophy of classification in epilepsy.

The Commission has produced a draft document of its recommendations which is intended for publication as a Commission report in the upcoming year. This draft updates definitions and concepts of focal and generalized as they are used to characterize seizures and epilepsies. It proposes new terms to replace idiopathic, cryptogenic, and symptomatic and new definitions to bring those concepts into alignment with our current understanding of causes of epilepsy. Guidelines are provided for the use of the term syndrome in reference to an epilepsy entity. The draft also provides a definition of the concept of epileptic encephalopathy.

A new approach and philosophy to organizing syndromes is proposed in which the current rigid classification is replaced by a flexible multidimensional organization. This will permit arrangement of epilepsies according to the features most salient for a given purpose. It will also allow incorporation of new features and dimensions as the need arises. Such an approach lends itself naturally to the future development of a diagnostic manual.

Recommendations for Future Work:

In order to develop the recommendations of this term's Commission further, the following steps will be required:

(a) Standardize the vocabulary used in epilepsy by updating and extending the ILAE's glossary of ictal semiology to include actual video examples. Develop similar glossaries for EEG (terms and examples) and MRI (terms and examples) as well as any other clinical or historical features that are essential for characterizing epilepsy and seizures. Ideally, these glossaries will be available to anyone on the ILAE Web site and will be modified over time as needed.

(b) Field test the glossaries to ensure that they are effective in standardizing the terminology used in epilepsy.

(c) Perform a large-scale demonstration of the feasibility and utility of the glossaries and the use of objective techniques to identify meaningful epilepsy entities and to provide guidance for determining the

(continued on page 48)

COMMISSION ON CLASSIFICATION AND TERMINOLOGY *(continued)*

most natural dimensions and meaningful dimensions for organizing information about epilepsy.

(d) Use the above information to develop a diagnostic manual which will become an Internet resource.

(e) With the help of multilingual colleagues, translate the glossaries and the diagnostic manual into as many languages as feasible.

Summary:

The Commission has completed the first major phase in modifying the approaches and methods used in classification of epilepsy and has pursued means of communicating these changes to the international epilepsy community. The next phase will be highly methodological and is intended (a) to advance the implementation of the new approaches outlined above, (b) to involve a broad range of epileptologists world-wide, and ultimately (c) to have a classification system and method that makes the classification of seizures and epilepsies as widely accessible as possible and responsive to change as necessary.

Anne T Berg
Chair

COMMISSION DIAGNOSTICS

List of Members:

William D Gaillard, Chair (USA)
John S Duncan (UK)
Demetrius Velis (Holland)
Sampsa Vanhatolo, Secretary (Finland)
Chong Tin Tan, Executive Committee, Ex-Officio

Aims:

The Diagnostic Commission received four goals from the ILAE President. Two goals fell under a Neuroimaging sub-commission chaired by Catherine Chiron and William D Gaillard, the other two under an EEG sub-commission directed by Demetrius Velis.

The Neuroimaging sub-commission was charged with developing an e-imaging course with EUREPA and establishing guidelines for imaging in children with epilepsy.

The EEG sub-commission was charged with extending the e-imaging EEG course and establishing use of portable EEG to underserved areas. A growing need is for expansion of e-courses availability in languages other than English.

Commission Activities:

Neurophysiology sub-commission. Demetrius Velis, Chair, Jean Gotman (Canada), Andreas Schulze-Bonhage (Germany), Kyriakos Garganis (Greece), and Leopold Gaston Boisy (Senegal).

Neuroimaging sub-commission: Catherine Chiron and William Davis Gaillard, Co-chairs, Matthias Koeppe (UK), Czaba Juhasz (USA), Fernando Cendes (Brazil), Rubin Kuzniecky (USA), Sang Kung Lee (Korea), and Fritz Woermann (Germany). J Helen Cross (UK) joined as an Ex-Officio member from the Pediatric Commission regarding our sub-commission mandate on pediatric imaging.

Task Force on Diagnostic Testing Study Guidelines: William D Gaillard (USA), Chair, J Helen Cross (UK), John S Duncan (UK), Hermann Stefan (Germany), and William H Theodore (USA).

Meetings/Workshops:

Singapore ILAE 2007: Evidence-based imaging in refractory pediatric epilepsy.

Budapest, Hungary IEC 2009: ILAE Commission Symposium: Imaging Language in Epilepsy.

Kusadasi, Turkey 2007. European Pediatric Neurology Conference ILAE/WHO initiative for infantile epilepsy guideline development.

Accomplishments:

Educational Courses

e-education EEG (throughout term)
e-education Imaging Neuroimaging 2007-2008, 2008-2009

Publications

Gaillard W D, Chiron C, Cross J H, Harvey A S, Kuzniecky R, Hertz-Pannier L, Vezina L G. Guidelines for Imaging Infants and Children with Recent-Onset Epilepsy. *Epilepsia* [e-Pub ahead of Print 6 April 2009].

Gaillard W D, Cross J H, Duncan J S, Stefan H, Theodore W H. Diagnostic Testing Study Guidelines & Practice Parameter Commentary. (Draft)

Gaillard W D, Chiron C, Cross J H, Harvey A S, Juhasz C, Woermann F, Hertz-Pannier L. Guidelines for Imaging Infants and Children with Medication Resistant Refractory Epilepsy. (Draft)

Summary:

Initial Goals and Accomplishments

The Neuroimaging Commission was charged with developing an e-imaging course with EUREPA and establishing guidelines for imaging in children with chronic epilepsy, which follows earlier guidelines for imaging children with recently diagnosed epilepsy.

The sub-commission, primarily due to the efforts of Dr Chiron, has devised an e-imaging course, with textbook, lectures, and course educational materials, including references, exercises, and test. The first course launched at Singapore with a series of lectures followed by a one-semester course with 12 students. This year preliminary lectures were given at Berlin, and the course extended by several weeks (each section from two to three weeks). Course enrollment for this year is 24. A modified version of this educational course is designed for Budapest.

The Guidelines are in draft form, but several sections remain lacking. The Commission sponsored a symposium at IEC Singapore that resulted in core material for the guidelines in MRI TLE, SPECT, and PET.

The EEG sub-commission was charged with extending the e-imaging EEG course and establishing the use of portable EEG to underserved areas. Dr Velis has been successful in extending the EEG courses but has found it difficult to work with local Chapters regarding EEG implementation. A growing need regarding expansion of e-courses is availability in languages other than English.

For educational objectives we have worked closely with the Educational Commission (Dr Jacobian) and EUREPA.

(continued on page 50)

COMMISSION ON DIAGNOSTICS *(continued)*

Additional Goals and Accomplishments

An additional initiative to draft guidelines for MEG was recommended by the Diagnostic Commission. There have been a number of recent reviews, but there remains a lack of critical appraisal of evidence.

Based on experience in drawing guidelines for AAN, ILAE, and WHO, it is apparent that the current guideline methodology for diagnostic testing is unsatisfactory. When charged with providing evidence-based guidelines for imaging in refractory epilepsy, it became clear that there are no ILAE criteria for establishing strength of evidence, which has hampered production of this document. There is an emphasis on “evidence-based” methods, but these are primarily derived for therapeutic trial. Their translation to diagnostic testing (imaging, MEG) is based on classification scales for diagnostic or prognostic testing. The Diagnostic Commission has established a sub-commission (Chair W D Gaillard with John Duncan, Helen Cross, Hermann Stephan, W H Theodore) to examine limitations to these methods and propose solutions as regards epilepsy.

Recommendations for Future Work:

The major challenge is the proper evaluation and use of technology and other diagnostic methods to improve care of patients with epilepsy when there is such a broad range of available technology and expertise across the globe. At one extreme is the optimal “best practices” in developed societies; the other is optimal use of limited resources in underdeveloped economies. These issues touch upon education as well as assessments and utilization of diagnostic methods. The two areas in which the Commission for Diagnostics has been most active are emerging diagnostic methods and disciplines.

1. Educational initiatives will continue to be important, though the target audiences and means of delivery will need to be re-evaluated. There have been several educational initiatives that have been successful despite limited support and exposure over the past eight years. A limitation of these courses was poor advertisement, held before the meeting, when the venue was not really open. Proposals to hold and modify similar educational initiatives were redirected four years ago to EUREPA and e-imaging courses. These courses were restricted to registrants for courses who often could not attend ILAE or a European meeting. There is wide latitude for reconsidering audiences and delivery of information. For example, a course might be held in the body of the meeting rather than before the meeting when the venue is not open, and should be more inclusive. The model of the American Epilepsy Society rotating educational courses as an evening (need not be evening) comes to mind. The e-course initiatives have the potential to reach more

widespread audiences and to provide positive impact in emerging medical care settings but has not realized its potential.

2. A continuing challenge is the proper evaluation and setting of standards for the use of technology in the evaluation and care of patients with epilepsy across the globe. It is apparent that the current guideline methodology for diagnostic testing is unsatisfactory. There do not appear to be any official ILAE criteria on which to base evidence-based guidelines. The ILAE will also need to decide what criteria it chooses for its guidelines. There are significant flaws in both AAN and WHO guidelines but it may be impractical to formulate tailored guidelines for ILAE. There is an emphasis on “evidence-based” methods, but these are primarily derived for therapeutic trials. Their translation to diagnostic testing (imaging, MEG) are based on classification scales for diagnostic or prognostic testing. As new technologies emerge it will be important to assure proper assessments are performed and disseminated. A challenge is for the ILAE to play a more active role in coordinating and conducting multi-site standardization and evaluation of diagnostic methods, not only among developed economies, but in emerging economies as well, such as the pediatric collaborative imaging initiative.
3. The revolution in genetics and the forthcoming diagnostic genetics will open new horizons and challenges. The Commission to date has been machine driven (EEG, MEG, MRI, PET, SPECT). That is about to change, not only in how genetics informs interpretation and use of technology but as a diagnostic discipline in itself. The view of diagnostic testing will need to be expanded with on-going genetic revolution with all its prospects and limitations.
4. Another emerging area that should attract the attention of the ILAE are evolving efforts to image biomarkers and targets for neuroprotection and intervention trials.

William Davis Gaillard, MD
Chair, Commission for Diagnostics

COMMISSION ON EDUCATION

Members:

Elza Márcia Yacubian, Chair (Brazil)
Esper A Cavalheiro (Brazil)
Milda Endziniené (Lithuania)
Hassan Hosny (Egypt)
Jeffrey Noebels (USA)
Margarete Pfäfflin, Secretary (Germany)
Perrine Plouin (France)
Alejandro Scaramelli, Treasurer (Uruguay)
Bettina Schmitz (Germany)
Chong Tin Tan (Malaysia)
Verena Hézser-v.Wehrs, Ex-Officio (Germany)
Emilio Perucca, Ex-Officio (Italy)
Peter Wolf, President ILAE, Ex-Officio
Solomon L Moshé, Secretary-General, Ex-Officio
Martin Brodie, Treasurer, Ex-officio

Meetings:

The Commission met at the AES (2005, 2006, 2007), at the European Congresses (2008), had a workshop in Paris in 2007 and otherwise conducted its business by mail. The Commission has published extended minutes, reports (2006, 2008 and Final 2009), the Global Education Agenda 2007 and flyers (<http://www.epilepsy-academy.org/>).

Aims:

All activities of the Commission focused on the one aim to develop a global structure for the education of all professionals working in the field of epilepsy and to design and implement an educational system which makes quality education in epilepsy globally available. We aim at having an educational system in epileptology which is unparalleled in any other field of medicine, and therewith attract the best talents to our field.

Commission Activities:

Within the last four years, the number and the quality of educational activities in epilepsy have increased significantly worldwide. The Commission has regularly reported about all activities and published the reports at the new Academy Web site: <http://www.epilepsy-academy.org>.

Accomplishments:

Academies:

EUREPA: The European Epilepsy Academy has been the pioneer of our educational agenda for ten years. EUREPA was set up by the Commission on European Affairs as a separate non-profit association with its own budget and employed personnel. With its experience, programs and services it is now taking care of transcontinental activities as well as the global educational programs. More suitable structures to meet this development are under discussion.

ASEPA: The Asian/Oceanian Epilepsy Academy is working similar to a sub-commission of the Commission on Asian and Oceanian Affairs but with a

term of office changing at mid-term of the CAO to ensure continuity. ASEPA has successfully developed an educational agenda with a regional flavor including scholarships, educational courses at Regional Congresses, a series of educational stand-alone courses in underserved countries and sub-regions, and EEG certification (in cooperation with the regional Societies of Clinical Neurophysiology).

ALADE: The 'Academia Latino-Americana de Epilepsia' was founded in São Paulo, in February 2007 by the Commission on Latin American Affairs, and has already provided a number of educational courses, mainly the LASSE courses.

Virtual Epilepsy Academy (VIREPA): Distance education can now be considered a well-established part of the ILAE educational agenda. Besides on-site courses and training, it is soon expected to become a third major carrier of global education for the ILAE. VIREPA has developed concrete suggestions on the diversification (development of new modules on comprehensive care, neuropsychiatric aspects etc.), and differentiation (different course formats) of the VIREPA program besides the continuation of already well-established courses.

Implementing educational programs:

Africa: On the background of the successful EUREPA Train-the-Trainers courses, new types of qualifying courses were developed where the Train-the-Trainers model was combined with education of local professionals. One focus was on healthcare professionals as they play an important role in epilepsy care. Details of activities of the Lusophone, Francophone and Anglophone section can be found in previous reports.

Summer schools and migration courses: Starting with the annual San Servolo Summer Schools, advanced courses have been established as a cornerstone of ILAE — organized education and are continuing. The BSSE — the Baltic Sea Summer School has its third edition in Kiel, Germany in June 2009 and the Caucasian Summer School in Tsaghkadzor, Armenia in 2008 will continue.

The Global Education Agenda & Epilepsy Academy: The Global Education Agenda defined objectives, strategies, ways and means of operation to implement a global educational system. The installment of the Epilepsy Academy in order to secure sustainable structures for education and to further develop high quality teaching programs was one step. The system of dissemination, sharing and exchange of knowledge, information and material between the ILAE Executive Committee, the Commission on Education, various sub-commissions and the Epilepsy Academy Office was summarized as "ILAE Epilepsy Academy."

(continued on page 52)

COMMISSION ON EDUCATION *(continued)*

ILAE Epilepsy Academy Web Site Information Portal & Knowledge Portal: By the end of term of this Commission, the Information Portal – as an integral part of the ILAE Web site dedicated to education – will be launched. This site makes worldwide ILAE educational activities visible, transparent, and accessible for applicants and will support organizers with appropriate information in their ambitions to provide high quality events.

The site is expected to add to the outstanding educational profile of the ILAE. The project proposal of an additional Knowledge Portal supplying ILAE members with educational material was submitted in June 2008 and its implementation is expected to follow within the next term of office of the ILAE.

Recommendations for Future Work:

Considering this demanding education agenda, we have selected four priority steps which are necessary to lay the groundwork for further educational activities and development of the ILAE. They also include the potential for fund-raising.

1. Promotion and Marketing

The VIREPA program has to be advertised in all suitable media, with respect to a broad spectrum of target groups and using different formats. Details have been developed by the ILAE Epilepsy Academy office in order to use educational activities as a source of income to the ILAE. The marketing campaign needs to be started at once.

Scrutinizing the possibility of extending the VIREPA courses with respect to numbers of participants and with respect to new topics is essential. More courses could be created. Courses on psychiatric problems, neuropsychiatry, and rehabilitation in epilepsy (which would be the first one worldwide) are in the pipeline.

It is expected that the new ILAE educational Web site will contribute to the promotion and marketing of ILAE educational activities worldwide.

2. ILAE Curriculum and Certification

Participants of certified courses, participants in training programs and visiting professorships need to know how all these components assemble to a profile as “certified epilepsy specialist”. Essentials to composing this curriculum have been started and need to be finished as soon as possible; last but not least to induce a smooth follow-up of different steps within the whole range of educational activities.

3. Education as the spearhead for development of epileptology in Africa

Africa has long been a problematic region for epileptology. This is about to change due to a series of educational activities which are related to the foundation of new ILAE Chapters in the Region. An

annual series of residential courses combining the aspect of training future African trainers and educating local staff (doctors and EEG technicians) has been organized by the Francophone sub-commission of the Commission on Education. These have taken place in France 2004, Tunisia 2005, Senegal 2006, Cameroon 2007, and Morocco 2008. The next courses were projected for Guinea 2009, Mali 2010 and Ivory Coast 2011. In all these countries but Cameroon, ILAE Chapters have been formed and in most instances already accepted. The Lusophone sub-commission with the support of the Portuguese and Brazilian Chapters has begun a similar series of courses in Brazil 2006 followed by Mozambique 2008. Here, the education included local “mental health technicians” who are responsible for primary care for epilepsy; also in Mozambique, an association was founded which is expected to become the national ILAE Chapter. A new course was planned for Cape Verde in 2009. More recently, following a residential course by the AES and IBRO, that prompted the foundation of an Ugandan ILAE Chapter, representatives of the ILAE Chapters of Australia, Canada, India, UK and USA have started to plan similar initiatives for Anglophone Africa. The Past President and First Vice President plan a course in Ghana promoting local epilepsy research as part of the ILAE’s new partnership with Basic Needs.

As it has become clear that such educational programs are a highly efficient and cost-effective way of developing the Region, the Commission on Education strongly recommends continuing with these and developing them further. Initially, sponsorship from inside the ILAE (AES, Brazilian, French and Portuguese Chapters, Commission on European Affairs and central funds via the Commission on Education) has been high, but all these courses have also received external funding from sources like the pharmaceutical industry, local governments and many others. In the future, the ILAE share should slowly decrease to make the courses more self-sustaining.

The current financial crisis probably means that the courses planned for 2009 (Guinea, Cape Verde and possible others) cannot take place. In order not to lose the developmental momentum that was created, we strongly recommend that these be put high on the priority list for 2010.

4. ILAE – Epilepsy Academy and Endowment Fund

The high potential of education in the field of epilepsy and the willingness of people to invest in education make the Academy an attractive showpiece for people who are not members of the ILAE.

At present, it costs the ILAE more to run its Epilepsy Academy than the revenue it generates through the VIREPA courses and other services. In addition, roughly

(continued on page 53)

COMMISSION ON EDUCATION *(continued)*

half of the present income is from bursaries provided by the ILAE and the CEA, and the other half from external sources. This needs to change in two steps. Step 1 is reached when the gross income of the Academy (i.e., including internal income) covers its running costs and step 2, when the net income (i.e., income from external sources) does the same and the Academy starts to generate net surpluses. Even then, the ILAE will probably continue to give bursaries for education with the purpose of developing certain regions or certain professionals allied with medicine.

To ensure better control and transparency, the Commission on Education proposes the establishment of an Educational Endowment Fund for both ensuring and limiting the resources used for education. Moneys which initially may be used for running the Academy will eventually be freed up for other educational purposes as determined by the ILAE Executive Committee.

The Commission on Education promotes a cooperation between the Executive Committee and the ILAE Epilepsy Academy. A person within the Executive Committee responsible for education had already been proposed in the Global Education Agenda. Additional ties could be created with an advisory group/Task Force active in the field of education, which would initiate future educational activities and serve as a lever for commitment, professional and financial resource mobilization.

Summary:

During the present term of office, the Commission on Education has tried to close the perceived advisory gap between the Academy, numerous educational activities and initiatives and the Executive Committee, within the limits of a new and inexperienced Commission. The Commission is grateful for having been given the opportunity to further develop an agenda which in our opinion is of vital importance for the ILAE. As our mandate ends much still remains to be achieved. Education is a stable currency for which knowledge and skills build the capital. Today both are rare. Therefore it is here we need to invest.

Elza M Yacubian
Chair

EPIDEMIOLOGY TASK FORCE

List of Members:

Ettore Beghi, Co-Chair (Italy)
Dale C Hesdorffer, Co-Chair (USA)
W Allen Hauser (USA)
Ley Sander (UK)
Torbjorn Tomson (Sweden)

Aims:

The Epidemiology Task Force was constituted in the Spring of 2008 and worked for the last year of the term. The aims of this Task Force were:

1. To formulate definitions of acute symptomatic seizure for epidemiological studies and, where definitions are not possible due to limited information, to formulate study designs to arrive at definitions. This activity was begun under the previous Epidemiology Commission;
2. To undertake an analysis of risk factors for SUDEP, a rare condition, by combining the four main published datasets and provide comparable data on potential predictors. This activity was originally proposed under the previous Epidemiology Commission but the Commission was unable to obtain all of the datasets. The datasets belong to Dr Hauser, Dr Tomson and Dr Sander and Dr Brodie.

Commission Activities:

The Epidemiology Task Force met three times: September 2008 at the 8th European Congress on Epileptology in Berlin; December 2008 at the American Epilepsy Society Meeting in Seattle; and February 2009 in Amsterdam. The purposes of these meetings were to discuss work that remained from the prior terms, to plan the work of the Task Force and to review the work accomplished. More specifically, the following activities were undertaken in subsequent steps:

1. Completion and revision of a manuscript on definitions of acute symptomatic seizures that had been submitted to *Epilepsia*;
2. Based on the weakest areas detected in the prior work (highlighted in the above mentioned manuscript), focus upon seizures in association with metabolic derangements and with prescription drugs to formulate optimal study designs to further clarify these definitions. This work has led to broad outlines for two manuscripts to describe the study designs and rationale for investigators pursuing the research;
3. Completion of a combined analysis of the four SUDEP datasets after reviewing the variables common to all four studies or subsets and categorization of these factors across studies. A paper based on this analysis is in preparation;
4. Discussion of future work that could be undertaken by the future Epidemiology Commission (see below).

Accomplishments:

The two main aims of the Task Force have been fully met:

1. A position paper has been completed with working definitions of acute symptomatic seizures with reference to selected epileptogenic conditions (with type and timing). Areas of uncertainty regarding metabolic and drug-related causes have been identified; the basis for evidence-based research aimed at clarifying some of these gray areas has been outlined through a summary of ad-hoc study protocols;
2. A pre-defined plan for a pooled analysis of the available databases on SUDEP was outlined, the analysis completed, and a manuscript on the main risk factors for SUDEP is in preparation.

Recommendations for Future Work:

We selected three areas important to the burden of epilepsy: mortality in epilepsy; comorbidity in epilepsy; and development of an epidemiological definition of Status Epilepticus. These issues overlap with one another and together describe a large proportion of the burden of epilepsy.

Mortality burden: The mortality burden of epilepsy has been a long-standing interest of the Epidemiology Task Force and goes back to the work of members of the previous Commission on Epidemiology. This previous Commission led by Allen Hauser addressed mortality and published an *Epilepsia* supplement [*Epilepsia* 46 (Suppl. 11), 2005]. However, none of the previous work has directly addressed potentially preventable causes of death in people with epilepsy worldwide. We propose that this work be done through a systematic review of causes of death in epilepsy, excluding those causes that are themselves epilepsy risk factors, because these are often independently associated with mortality (e.g., stroke, Alzheimer's disease, CNS infections). Both SUDEP and completed suicide would be addressed in this review and the hope is that other causes of death in epilepsy would also be identified as potentially preventable. After identifying the preventable causes of death, a systematic review would be done to identify risk factors for these causes of death. This information would be used to develop potential prevention strategies. We foresee several educational activities associated with this task through symposia at meetings.

Comorbidities: Epilepsy comorbidities are increasingly appreciated as conditions that need to be addressed over and above seizure control. Little is known about the full spectrum of these comorbidities. The most studied have been the psychiatric disorders for which a known mental health gap exists in their recognition and treatment that has recently been targeted by a WHO initiative. A systematic review of the epilepsy comorbidities (psychiatric, neurologic, and somatic)

(continued on page 55)

EPIDEMIOLOGY TASK FORCE *(continued)*

would be a useful resource for the epilepsy community. To the extent possible, the review would address which comorbidities are associated with an increased risk for epilepsy, which develop after epilepsy and which have been examined only in cross-sectional studies, so directionality, if any, is uncertain. Additionally, prognosis of epilepsy in the setting of specific comorbidities would be addressed whenever possible. Part of this work would involve assembling a list of validated instruments to assess epilepsy comorbidities, indicating the languages in which they are available, the time to administer them and whether they have been validated in people with epilepsy.

Status Epilepticus: Clinical definitions of prolonged seizures/Status Epilepticus have slowly moved from a duration of 30 minutes or more to one of at least five or ten minutes. The reasons for these changes are different from the processes that guide construction of meaningful epidemiological definitions. Because prolonged seizures may adversely affect prognosis in several ways (e.g., mortality as well as development of mesial temporal sclerosis with its associated sequelae), a systematic review of the literature on the incidence and prognosis of prolonged seizures is worthwhile to develop an epidemiologically meaningful definition of Status Epilepticus for use in future studies.

Summary:

An Epidemiology Task Force was constituted in the Spring of 2008 to conclude the activities of the previous ILAE Epidemiology Commission, and to carry out two new tasks: 1. To provide definitions for acute symptomatic seizures for epidemiological studies; 2. To undertake an analysis of risk factors for sudden unexplained death (SUDEP).

A position paper was prepared with working definitions of acute symptomatic seizures for each main epileptogenic condition. Areas of uncertainty on metabolic and toxic causes of acute symptomatic seizures have been identified and summary protocols for the investigation of metabolic and drug-related seizures have been outlined. A pooled analysis of four existing databases on SUDEP (from the USA, Sweden, England and Scotland) has been completed to set the basis for the preparation of a scientific document. In addition, the Task Force identified a number of areas regarding the burden of epilepsy to set the activities of future epidemiology commission work. These include the mortality burden, comorbidities, and Status Epilepticus.

Ettore Beghi and Dale Hesdorffer
Co-Chairs, Epidemiology Task Force

COMMISSION ON GENETICS

Members:

Ruth Ottman, PhD, Chair (USA)
Shinchi Hirose (Japan)
Satish Jain (India)
Holger Lerche (Germany)
Isclia Lopes-Cendes (Brazil)
Jeffrey L Noebels (USA)
Ingrid E Scheffer (Australia)
José Serratosa (Spain)
Federico Zara (Italy)
Frederick Andermann, ILAE Executive Committee
Liaison (Canada)

Aims:

- To facilitate the identification of human epilepsy genes on a worldwide scale.
- To make the results of genetic research on the epilepsies readily accessible to clinicians.
- To improve the public understanding of genetic factors in epilepsy.
- To work with related ILAE Commissions to increase understanding of genes that affect risk for epilepsy, including the phenotypes they influence and their role in basic mechanisms of epileptogenesis and anti-epileptogenesis.

Commission Activities:

Meetings:

4 December 2006
10 July 2007
4 December 2007
7 December 2008

Projects:

1. Preparation of report on Genetic Testing in the Epilepsies. This was our highest priority during the current term.
2. Two Commission-sponsored symposia
 - **Epilepsy Genetics in the 21st Century: Building Bridges from the Laboratory to Patient Care.** Full-day symposium held at the 27th International Epilepsy Congress (Singapore, 2007), co-sponsored with the Neurobiology Commission;
 - **Genetic Testing in the Epilepsies.** Teaching Session to be held at the 28th International Epilepsy Congress (Budapest, 2009).
3. Review and oversight of the Epilepsy Genetic Association Database (EpiGAD), an online database developed by Nigel Tan, MD and Samuel Berkovic, MD (www.epigad.org).

Accomplishments:

Commission Report. The report entitled "Genetic Testing in the Epilepsies" has been completed. The word "Guidelines" was intentionally omitted from the title because Commission members were concerned about the medico-legal implications of using this term. For example, if the report were considered an official guideline, in some settings medical providers might be subjected to legal action if they did not carry out a genetic test. The report is a current summary of the gene discoveries of major importance in the epilepsies so far, and their clinical implications, written in language understandable to epileptologists who are not primarily engaged in genetic research. It provides background about genetic testing in general and presents a framework for considering the clinical utility of a genetic test that can be applied to new genes discovered in the future as well as to currently known genes. We shall submit this document to the ILAE Executive Committee for approval before submitting it for publication in *Epilepsia*.

Establishment of Commission as Sponsor of EpiGAD Web site. With the approval of the ILAE Executive Committee, the Commission assumed the official role of sponsor of the EpiGAD site. This is consistent with one of the aims of the Commission in facilitating the identification of genes that influence risk for epilepsy on a worldwide scale. By adding its endorsement to the site, the Genetics Commission hopes that epilepsy researchers will be encouraged to use it and submit their unpublished data, as well as pointing out any studies that may have been missed by the site developers.

We appointed a sub-committee including Holger Lerche, Jose Serratosa, and Satish Jain, who would be responsible for monitoring the site twice yearly, and reporting back to the full Commission after each review. In addition, one or both of the site developers (Sam Berkovic or Nigel Tan) have been asked to attend one Commission meeting per year to report on the site activities and usage. The criteria to be used for monitoring include general functionality of the site, completeness, and accuracy. Following each review, the sub-committee sends a brief report to the site developers summarizing the results of their review, with recommendations for improvement if applicable.

Recommendations for Future Work:

The Genetics Commission has established three priorities for future work in the next term.

1. Promote education about epilepsy genetics for other epilepsy professionals and the wider public. The rapid pace of genetic research on the epilepsies,

(continued on page 57)

COMMISSION ON GENETICS *(continued)*

combined with generally inadequate education about genetics in the course of medical training, makes it extremely difficult for practicing epileptologists to keep abreast of recent discoveries and interpret their implications for clinical practice. This problem is even more pressing for the general public. Accordingly, providing education about epilepsy genetics for other epilepsy professionals and the wider public is one of our highest priorities. The Genetics Commission should develop educational materials directed to professionals and the lay public respectively, and these should be posted on the ILAE Web site and translated into multiple languages for use by local Chapters. These materials, prepared in a culturally sensitive manner, could help to combat stigma and discrimination related to genetics. Similar materials have been prepared by the Epilepsy Foundation for use in the USA, but providing education in an international context is an important challenge.

For epilepsy professionals, educational sessions at epilepsy Congresses worldwide should also continue during the next term. Also, the Genetics Commission could assume a more formal role in assisting with the genetics module of the VIREPA (Virtual European Epilepsy Activity) course.

2. Provide access to genetic research results for use by researchers. The rapid pace of genetic research also makes it challenging for epilepsy genetics researchers to keep track of the vast accumulation of new information. The Genetics Commission could play an important role in compiling and providing access to research findings for use by researchers. One example of this type of activity is the EpiGAD Web site, which summarizes the findings of allelic association studies in the epilepsies. In the next term we envision further developments in this vein, taking advantage of the Genetics Commission section of the ILAE Web site. This would involve providing links to existing sites, including EpiGAD and a recently developed site developed by Lossin (UC Davis) that compiles data on identified mutations in SCN1A (<http://web.scn1a.info>). As a first step, the Commission could identify the sites that are currently available and provide links to those it considers useful for researchers in the field. Development and promotion of the Genetics Commission section of the ILAE site for use by researchers would require some support from the ILAE, but could be enormously helpful in facilitating genetic research and clarifying genotype-phenotype relations in the epilepsies. Nigel Tan, an epileptologist with both genetics and Web site development expertise, would be an excellent addition to the Commission to assist with these activities.

3. Promote and facilitate international collaboration among investigators carrying out large-scale genetic studies. Probably the biggest challenge for the next decade of genetic research, in epilepsy as in other disorders, is the identification of genes that influence risk for genetically complex epilepsies and pharmacologic response to antiepileptic medications. Genome-wide association studies (GWAS) are the most promising method for identifying these genetic effects, and several groups in Europe and the USA are actively engaged in carrying them out. In part because of the huge number of statistical tests that are carried out in any single GWAS (many hundreds of thousands of markers are tested for association with a given phenotype), replication of any "significant" findings that emerge is essential for validation. Replication can be accomplished within a single study if the sample is split and analyzed in two stages – but of course this reduces power. Consequently, to move the field forward as rapidly as possible, communication at a minimum, and preferably collaboration among the different studies is critical. Thus one of the Genetics Commission's highest priorities for the next term is to promote and facilitate international collaboration among investigators carrying out large-scale genetic studies, particularly focusing on GWAS.

The methods for promoting collaboration remain to be worked out. However, we could explore the possibility of creating a Web site where de-identified data could be entered by the different investigators, for common access by all who agree to share data. Another issue is variability in phenotype categories across the different studies, and it might be possible to introduce some standardization of data elements or phenotypic categories. It would be important to have a small meeting to discuss these issues during the next term; possibly we could have an educational session for epilepsy professionals followed by a closed meeting of investigators currently carrying out GWAS.

Summary:

Our highest priority during the current term was to create a report on genetic testing that would be understandable and useful for practicing epileptologists who increasingly need to confront genetic findings in their daily work. We hope that our completed report will be well received and widely used. In the next term, we will continue to address the Commission's aims by developing additional educational materials and promoting genetic research on the epilepsies.

Ruth Ottman
Chair, Commission on Genetics

COMMISSION ON NEUROBIOLOGY

List of Members:

A Vezzani, Chair (Italy)
E Bertram, Secretary (USA)
C Bernard, Treasurer (France)
H Beck (Germany)
M de Curtis (Italy)
J Engel (USA)
I Mody (USA)
Y Murashima (Japan)
J Noebels (USA)
M Nunes (Brazil)
A Pitkanen (Finland)
Y Yaari (Israel)
G Avanzini, Ex-Officio (Italy)
S L Moshé, Ex-Officio (USA)
J Swann, Ex-Officio (USA)
P Schwartzkroin, Ex-Officio (USA)

Aims:

Our Commission activities have been focused on the planning and accomplishment of the initiatives elaborated and discussed at the beginning of our mandate in 2005, as reported below in detail. New initiatives that should be realized in the future to continue the main mission of this Commission, i.e., to promote translational research, are described at the end of this document. Our efforts were directed into three main areas of intervention, in strict collaboration with the ILAE Commissions on Therapeutic Strategies, Genetics and Pediatrics, as well as with the Education Commission:

1. Organization of teaching courses to bridge basic and clinical research;
2. Organization of workshops and basic science sessions within the scientific program of the main international meetings on epilepsy;
3. Initiatives on new therapeutic strategies.

Commission Activities and Accomplishments:

1. Educational activities

In collaboration with the Educational Committee (E Cavalheiro, Chair) we have contributed to *The first Latin-American Summer School on Epilepsy (LASSE)* held in Brazil in 2008. The title of the school was "Epilepsy: Translating Basic Knowledge into Clinical Applications." Distinguished epileptologists from different countries (focusing on those working in Latin-American countries) were invited to act as speakers and/or tutors to offer lectures and practical sections to post-graduate students working in Latin America. Since this initiative was successful and participants were enthusiastic about a repeat of this training activity, our Commission gave support and collaboration for the organization of a second LASSE school to be held in 2009. Our Commission has also played a role in assisting local committees with the organization of

other educational activities in Central and South America, i.e., the 5th Latin America Epilepsy Congress held in Montevideo in 2008.

The ASEPA Course, held before the IEC in Singapore in 2007, is another example of the Commission's active engagement in educational activities. The purpose of this course was to introduce clinicians to the work of basic scientists and allow for basic scientists to listen to the concerns of clinicians. The ultimate goal was to enlighten clinicians to the advances in basic epilepsy research and help them interpret the results in a clinical context. The course included lectures ranging from understanding the significance of whole animal studies to interpreting the clinical relevance of information from in vitro models. The role of genetic studies in identifying potential clinical applications was also discussed. The steps necessary to identify new treatments either for preventing epileptogenesis or reducing pharmacoresistance was an important focus of this course, and represents one topic of intense discussion between our Commission and the Therapeutic Commission (see below). By the end of the symposium, the participants were exposed to discoveries in basic sciences and how these can lead to new approaches in the diagnosis and treatment of the epilepsies and their consequences.

The San Servolo International School Our Commission has significantly participated in the tutoring activities of this International School, and in 2008, seven of our Commission members participated as tutors or lecturers. In 2009, the course: "Bridging basic science with the clinic" will involve a new initiative promoted by our Commission and the organizers (G Avanzini and M de Curtis). An alumni meeting of the San Servolo students will be held in 2009, in association with WONOE where the most promising students who attended the school in the past years were invited to present their work and to discuss their ongoing activities. Moreover, the students were invited to participate for one day in the WONOE and present their work in a poster format. Their presentations were also eligible for oral communication depending on the topic and their scientific value. This new initiative should be viewed as a way to evaluate how this school has contributed to fostering the development of the student's career and to permit the students to play active roles in presenting their findings.

Workshop on Neurobiology of Epilepsy (WONOE) The Commission has organized two WONOE during its mandate, namely the one associated with the ILAE Singapore meeting in 2007 entitled "The Transition from the Interictal to the Ictal State" and the one to be held in Pécs in association with the ILAE Budapest meeting, entitled "New targets for antiepileptic strategies." As explained above, this year the

(continued on page 59)

COMMISSION ON NEUROBIOLOGY *(continued)*

WONOEPE has a different feature since it includes the participation of the San Servolo School students.

2. Organization of symposia and basic science sessions within the scientific program of the main International Meetings on Epilepsy

We have been involved in basic science session organization and presentation in all international epilepsy meetings organized from 2005 to 2009, including AES, European Congress on Epileptology, and the International Congress on Epilepsy. Our Commission organized the Neurobiology Symposium at the ECE in Helsinki in 2006 and in Berlin in 2008. In particular, at the IEC in Singapore, ten basic science sessions were presented and a report about these sessions has been published in *Gray Matters of Epilepsia* (vol. 49, p. 359, 2008). At the IEC in Singapore we, for the first time, obtained full support for the basic scientists acting as invited speakers at the main sessions, thus allowing a significant increase in participation of basic science to this clinically oriented meeting. The ILAE Executive Committee took this into consideration for the following meetings and at the ICE in Budapest basic scientist participation in the main sessions and symposia will be again fully supported.

The Commission on Neurobiology has worked in close collaboration with the Therapeutic Commission and the Commissions on Genetics and Pediatrics. As an example of these interactions, at the ICE 2009 in Budapest, there will be two joint sessions presented in the main program, namely one session on Neonatal Seizures and one session on Cortical Dysplasia and Epilepsy. This last session will summarize recent studies highlighted in the October 2008 international meeting on cortical dysplasia (CD). The CD meeting, organized by the Commissions on European Affairs, Therapeutic Strategies, Neurobiology, and Pediatrics, brought together experts from multiple clinical disciplines to review "what is new" in clinical and basic science CD research. A review document of this meeting, also reporting guidelines on novel criteria of classification on type 1 CD, will be published in a supplement format in 2009.

3. Initiatives on new therapeutic strategies

To seek ways to improve the current process of preclinical screening, the League's Commissions on Neurobiology and on Therapeutic Strategies have joined on a new initiative to revisit the current methods of antiepileptic drug screening, with the goal of enhancing the existing screens in a way that will predict ultimate clinical efficacy/effectiveness at least for some forms of epilepsy. Under the aegis of the ILAE Executive Committee, leading members of these two Commissions have created The ILAE Neurobiology/Therapeutic Strategies Joint Task Force (members: Annamaria Vezzani, Jackie French, Ed Bertram, Christophe Bernard, Mike Rogawski, Gary

Mathern, and Nico Moshé) to conduct a research project with the aim of obtaining insights into the validity of models used in the identification of anticonvulsant/neuroprotective activity. In its initial phase of work, this sub-commission has evaluated the predictive value of the existing preclinical screens. A key part of this initiative was a brainstorming meeting held in Philadelphia in 2007 before the AES meeting, with the involvement of academic epilepsy researchers, NINDS representatives and the pharmaceutical industry to discuss which battery of screening tools should be used to bring new and more effective treatments to patients. The inclusion of potential new screens, including models of neonatal seizures and models of spontaneous seizure, were also discussed. The goals are to provide a more accurate prediction of clinical success, encourage the selection of truly promising compounds for clinical development, and to design interventions aimed at curing several forms of epilepsy not merely developing symptomatic treatments. The achievement of these goals requires additional work by the Commissions to promoting further initiatives for discussion and working on consensus on still controversial issues.

4. Other activities

We discussed during the San Servolo International School in 2008, a translational approach document that was prepared and presented to ILAE EC the same year.

Recommendations for Future Work:

We strongly feel that the Commission should continue to work and develop its mission. We would like to indicate some priority tasks for the next term of office, and make the basic science community more aware of the clinical issues of epilepsy that are relevant to their research. We discussed during the San Servolo International School in 2008, a translational approach document that was prepared and presented to ILAE EC the same year.

The three most challenging issues to meet these missions are the following. These points are listed in order of feasibility:

1. Exchange of knowledge between basic science and the clinic and from academia to the public. *The critical issue is to have the Neurobiology Commission and basic science involved in Program Committees of Meetings and Training Courses to make sure that basic science stays on the podium.*

- A basic requirement is that clinical symposia/programs have, wherever possible, a focused and relevant basic science component and for a basic science program there is a relevant clinical component.

(continued on page 60)

COMMISSION ON NEUROBIOLOGY *(continued)*

- The regular organization of balanced basic/clinical workshops on the state of the art of knowledge and treatments in a specific area, with the aim of discussing what has been achieved and how to improve knowledge in that field. Importantly, how the new knowledge can influence the ongoing treatment strategies. Outcomes of these initiatives should be published in scientific journals to make the information available to the scientific and clinical audience.
- The systematic involvement of media at national and international levels to raise awareness of basic science research in epilepsy in the general population and improve funding opportunities. This task will require collaboration with ILAE Press Office and Foundations such as CURE, PACE, Telethon, etc.
- Training basic scientists to clinical epileptology.

2. Establish networks of promising students

(from San Servolo School, LASSE or others) to communicate about local needs in poor countries in order to help to develop training programs in loco or abroad to meet these needs.

- Foresee the availability of training fellowships for clinicians and researchers in poor countries to visit centers of excellence under the supervision of tutors listed on an ad-hoc Web site.
- Make seed grants available for developing their own research projects upon return to their countries of origin.

This task will require establishing collaborative efforts among ILAE and other scientific associations, such as IBRO and FENS not only to divulge basic science discoveries but also to support training programs in countries under development.

3. To improve translation of basic science discoveries to the clinical setting for the development of more effective/less toxic AEDs.

How to achieve this task should be discussed extensively. A previous attempt by the Commission was to propose the following strategy:

- a. The creation of a network of scientists and clinicians of international reputation dedicated to drug development. This network should establish the still unmet clinical needs related to the treatment of epilepsy and how these needs could/should be addressed by basic science.

- b. The creation of an infrastructure based on international ground which includes experimental laboratories and clinical centers of excellence. This infrastructure is devoted to investigating the priority issues established by the above mentioned network (for example the development of novel models of seizures and epilepsy; the in-depth characterization of chronic models with common/shared criteria for their validation as clinically relevant models; define common outcome measures and their evaluation; protocols of drug treatment; the search for biomarkers for disease development and drug efficacy; testing a new promising putative therapeutic agent or a novel treatment strategy). This network of scientists and clinicians should work in concert whenever possible, and should be available to validate in a clinical setting the experimental findings emerging from the ongoing preclinical studies. Partners can be involved in distinct projects depending on their specific competences or major interests.
- c. Establish a regular meeting with industry to discuss potential new approaches to drug discovery and the validation of drug targets as likely paths to successful new therapies.
- d. Establish a virtual bank of brain and peripheral tissues from acute and chronic experimental models that should be made available for collaborative studies among the network groups. A Web site reporting the available material and its origin, from which lab, and all required information about tissue preparation (frozen, fixed, etc.) that can be shared with the community.

These tasks require the collaborative efforts of at least the ILAE Therapeutic Commission; fund-raising is an important issue that could be sought with a partnership with NINDS, private foundations (CURE, PACE etc), and drug companies (probably SME since big Pharma is less likely to contribute).

Annamaria Vezzani
Chair, Commission on Neurobiology

COMMISSION ON NEUROPSYCHIATRIC ASPECTS

The Commission on Neuropsychiatric Aspects has had a very dynamic and fruitful period. With four sub-commissions and two Task Forces, we set off on our journey with a clear agenda, which we are well poised to complete. With wide international representation, the Commission has taken a truly global approach in its deliberations.

Members:

J Trollor, GCP; Disability; Secretary (Australia)
Marco Mula, Research; GCP (Italy)
W LaFrance, Transcultural and Psychological Therapy Task Force (Co-chair); Disability (USA)
A Ettinger, Education – Chair; GCP (USA)
A Kanner, Research; GCP (USA)
B DeToffol, Member (France)
Bettina Schmitz, GCP; Research; Chair of last Commission (Germany)
ES Krishnamoorthy, Chair of Commission; Chair sub-commission on Disability (India)
F Besag, Transcultural Aspects; Disability; GCP (UK)
K Kanemoto, Disability; GCP (Japan)
L T van Elst, Research – Chair; Disability; GCP (Germany)
M Kerr, Good Practice Guidelines – Chair; Disability; Research; Treasurer (UK)

Meetings & Workshops:

A quorum, and in most instances many more than a quorum of members, convened at the following closed door meetings. The work of the sub-commissions was discussed and initiated during these meetings, with much of the work being completed as well.

July 2007, Chennai, India, T S Srinivasan Centre
4 Days

- Introductory Meeting of Commission/sub-commissions
- Delphi consensus exercise of the clinical practice statement sub-commission
- Piloting educational module
- Initial discussion on epilepsy and disability

December 2007, Philadelphia, AES
4 Hours
Business Review Meeting

February 2008, Chennai, India, T S Srinivasan Centre
3 Days

- Workshop of Task Forces – trans-cultural aspects and psychological therapies (together with Treatment Commission members)
- Workshop on Epilepsy and Disability sub-commission

September 2008, Berlin, Germany, Charite
1.5 Days
Workshop of the sub-commission on research priorities

December 2008, Seattle, USA, 3 Hours
Business Review and Future Planning Meeting

May/June 2009, Budapest (proposed), ILAE Congress
1.5 Days

Wrapping up workshop of all sub-commissions and Task Forces (subject to approval and release of funds for this activity)

Sub-commissions, Task Forces & Output:

Good Clinical Practice (GCP) Statements

Chair: Prof Michael Kerr (UK)

Objectives and Work Accomplished

- To develop using the scientific Delphi method of consensus building, a series of good clinical practice statements for neuropsychiatric disorders in epilepsy
- Face-to-face consensus meeting to identify key priority areas needing GCP statements
- Preliminary rounds of priority e-discussion (global)
- Secondary round of e-feedback (global)

Current Stage and Proposed Outcome

- Tertiary round of statement development is ongoing
- A Commission report is under preparation by the Chair and will be ready in March 2009 for discussion and finalization among Commission members
- The report will be finalized at the time of the International Epilepsy Congress in Budapest and submitted immediately thereafter

Research

Chair: Prof Ludger T van Elst (Germany)

Objectives and Work Accomplished

- To develop a position statement on research methods and priorities
- A full 1.5 day workshop dedicated to the development of research priorities was completed in Berlin as a pre-conference activity to the European Epilepsy Congress
- The workshop consisted of several key presentations and interactive discussions by Commission members

Current Stage and Proposed Outcome

- A position statement on development priorities is under development by the Chair based on these presentations and discussions and will be ready for e-discussion by Commission members in March 2009
- The report will be finalized at the time of the International Epilepsy Congress in Budapest and submitted immediately thereafter

Epilepsy & Disability

Chair: Prof E S Krishnamoorthy (India)

Objectives and Work Accomplished

- To develop a clinical construct, classification and health policy paradigm for disability in epilepsy

(continued on page 62)

COMMISSION ON NEUROPSYCHIATRIC ASPECTS *(continued)*

- Collaboration with the Indian Epilepsy Association (IBE Affiliate) and Indian Epilepsy Society (ILAE Affiliate) working group on the subject
- Two workshops: One for one day (July 2007) and one for two days (February 2008); detailed discussion of cross-national perspectives on disability
- A full Commission report is under preparation by the Chair and will be ready for e-discussion by Commission members in March 2009

Current Stage and Proposed Outcome

- The report will be finalized at the time of the International Epilepsy Congress in Budapest and submitted immediately thereafter

Transcultural Aspects (Task Force)

Chair: Prof F Besag (UK)

Objectives and Work Accomplished

- To develop a position statement on transcultural research priorities in Neuropsychiatry of Epilepsy
- Half-day closed door meeting in Chennai, India in February 2008
- Presentation by Chair and brainstorming

Current Stage and Proposed Outcome

- A summary of the discussions was prepared by Dr William La France, Task Force member
- A position statement on transcultural research priorities is under preparation by the Chair and will be integrated into the Research subcommission report

Psychological Therapy (Task Force – Jointly with the Treatment Commission)

Co-chairs: Dr Nandan Yardi (India)

Dr William La France (USA)

Objectives and Work Accomplished

- To develop a position statement on the role of psychological therapy in epilepsy
- Half-day closed door meeting in Chennai, India in February 2008
- Two representatives of the Treatment Commission, Dr Nandan Yardi (India), Chair sub-commission and Prof S C Schachter (USA) attended this meeting

Current Stage and Proposed Outcome

- A summary of the discussions was prepared by Dr William La France, Task Force member
- A position statement on psychological therapy research concerns and priorities is under preparation by the Chairs jointly

Output:

- Three Commission reports will be submitted to the ILAE Executive in June 2009 with a view to *Epilepsia* submission and publication.
- One Task Force report will be submitted to ILAE.
- The Commission has four symposia at the forthcoming Budapest Congress and all commission members will be taking part in this effort.

Pending Work:

- The education sub-commission chaired by Prof A Ettinger began the process of pooling all recent

committee presentations into a future Internet-based core curriculum. This work is ongoing and it is therefore recommended that it be developed by a future commission.

- Prof F Besag has this year initiated a project together with the ILAE Pediatric Commission and the IBE, examining the life experience of children with epilepsy and their families. This Task Force activity has true transcultural potential and will provide rich narrative data about children living with epilepsy across cultures. This being an important activity area, I would recommend that it remains on the agenda that is taken forward by a future Commission.
- The Commission is proposing a day-long symposium on “Epilepsy & Disability – A Gender and Lifespan Perspective” at a future AES meeting and hopes to develop a full journal supplement on this subject. Prof Andy Kanner (USA) is leading this effort.
- Commission members are collaborating on and initiating several cross-national projects relating to mood in epilepsy and neurobiology of behavior in epilepsy.

Summary:

The present Commission on Neuropsychiatric Aspects has been very productive, in the rather short period of its existence. Future directions for this Commission will include:

- The development of unified international research protocols to study the neuropsychiatric aspects of epilepsy systematically;
- Research efforts linking neurobiology with behavior and the systematic planning of their future study integrating available technology (one session at the Budapest Congress will address this theme); a particular focus of study will be mood and anxiety disorders;
- The development of integrated international health policy for people with epilepsy and neuropsychiatric comorbidity (the work on epilepsy and disability is the beginning of this development).

I have no doubt that all the members of this Commission, who have worked together admirably, as a well oiled machine, will be delighted to contribute munificently to these future efforts, when called upon to do so. I feel privileged to have been part of this dynamic international group and to have served as its Chair and co-ordinator. My heartfelt thanks are due to every member of this Commission for their generosity of time and industry, and to the outgoing President Prof Peter Wolf and the ILAE Executive Committee for having accorded me this wonderful privilege.

Ennapadam S Krishnamoorthy

Chair, Commission on Neuropsychiatric Aspects

COMMISSION ON PEDIATRICS

List of Members:

J Helen Cross, Chair (United Kingdom)
Alexis Arzimanoglou (France)
Tallie Z Baram (USA)
James Butler (South Africa)
Renzo Guerrini (Italy)
Nebosja Jovic (Serbia)
Eli M Mizrahi (USA)
Doug Nordli, Secretary (USA)
Makiko Osawa (Japan)
Hanan El Shakankiry (Egypt)

List of sub-commissions and members

Joint Pediatric Surgical Task Force with Therapeutics Commission; Chairs G Mathern and J H Cross

Aims:

To broaden international understanding of diagnosis and management of epilepsy in childhood

Commission Activities:

Meetings

1. **Commission meetings:** San Diego December 2006, San Servolo August 2007, Philadelphia December 2007, September 2008 (teleconference), Seattle December 2008;
2. **Surgical Task Force meetings:** San Diego December 2006, Singapore July 2007, Philadelphia December 2007, Seattle December 2008;
3. **Workshop on management of seizures in infancy:** organized conjointly at EPNS biennial meeting September 2007 in Kusadasi, Turkey;
4. **Meetings with WHO re: neonatal guidelines:** November 2007, March 2009 Troina, Sicily.

Subcommission activities

1. **Epilepsy surgery:** Collection of outcome data from 2004 survey; outcome in children undergoing surgery in 2004, due presentation IEC July 2009;
2. **Guidelines:**
 - a. Completion of guidelines for management of neonatal seizures (joint with WHO)
 - b. Proposal for development of guidelines for management of seizures in infancy;
3. **Adolescent survey:** survey of services currently available worldwide;
4. **6th International Course on Epilepsy:** 'Clinical and Therapeutic Approaches to Childhood Epilepsy' (Course Directors H Cross and B Dalla Bernardina), San Servolo, Venice 2007.

Joint projects with other commissions

1. Therapeutics Commission: Surgical survey;
2. Classification Task Force: D Nordli and J H Cross representatives;
3. Neuroimaging & Task Force for Classification: Seizures in infancy workshop;
4. Neurobiology: Representation (Tallie Z Baram), with joint neonatal seizure parallel session to be held at IEC.

Publications

1. Cross J H, Jayakar P, Nordli D, Delalande O, Duchowny M, Wieser H G, Guerrini R, Mathern G M, Proposed criteria for referral and evaluation of children with epilepsy for surgery *Epilepsia* 2006;47:952-959 UI:16822241.
2. Co J P T, Elia M, Engel Jr J, Guerrini R, Mizrahi E M, Moshé S L, Plouin P. Proposal of an Algorithm for diagnosis and treatment of neonatal seizures in Developing Countries. *Epilepsia* 2007;48:1158-1164.
3. Harvey A S, Cross J H, Shinnar S, Mathern G W and the Paediatric Epilepsy Surgery Survey Task Force. Defining the spectrum of international practice in paediatric epilepsy surgery patients. *Epilepsia* 2008;49:146-155 UI 18042232.

Accomplishments:

1. Epilepsy surgery

Work has continued in the evaluation of further epilepsy surgery practice in children worldwide. This work has continued jointly with the Therapeutics Commission under the chairmanship of Gary Mathern and Helen Cross. A retrospective survey of all procedures performed in 20 centers across the USA, Europe and Australia in 2004 was initiated in the previous term following previous recommendations. Data were obtained from a Web-based survey with data made available on 543 patients under the age of 18 years (Harvey et al: *Epilepsia* 2008. 49; 146-155). This data confirmed many of the perceptions with regard to pediatric epilepsy surgery, namely the age spectrum, range of procedures and common pathologies. This study demonstrated the power of collaborative working and answered key questions. A further study of outcomes from this 2004 cohort has been undertaken including data from a total 46 centers (all 20 original centers and 26 new centers) with 1,124 patients and evidence that only 10% of data cannot be used in follow-up evaluation. Only one WHO region is not represented in this study (Africa). No centers in Africa performing epilepsy surgery in 2004 were identified. Analysis is in progress and presentation of the results planned at a session at the International Congress in Budapest in July 2009. Subsequently full manuscripts will be prepared and submitted for publication.

2. Guidelines

i) *Neonatal* The Commission has continued to collaborate with the WHO in the development of guidelines for the management of neonatal seizures. This was initiated during the last term of office of the Commission of Pediatrics. As a result a proposal for an algorithm for diagnosis and treatment of neonatal seizures in developing countries was prepared and published in 2007 (Co et al: *Epilepsia* 48 1158-1164). Following further discussion however, it was evident that any such guidelines needed to be constructed with an

(continued on page 64)

COMMISSION ON PEDIATRICS *(continued)*

evidence base through structured methodology and therefore further work has been ongoing during this term to address this. Key clinical questions were outlined following a meeting in Troina in Sicily in November 2007. Individuals were recognized (including members of the Commission E Mizrahi and N Jovic) to address each of these key clinical questions with an evidence base via the GRADE methodology and a further meeting in Sicily in Troina in March 2009 led to final recommendations being drafted. Finalization of these is now in progress with the aim of completing such by the time of the IEC in 2009. A workshop has been accepted to discuss practice as to the management of neonatal seizures around the world, including speakers from India, Brazil, Uganda and Japan. Individual speakers will outline how the original algorithm relates to practice in their countries. An overview of the guidelines will be presented with plans to ultimately submit for publication later in the year.

ii) *Infancy* Plans were made for continuation of the work beyond neonates to the development of guidelines for the management of seizures in older children. A workshop was organized in conjunction with the European Pediatric Neurology Society during their biennial meeting in Kusadasi, Turkey in September 2007. This was attended by six members of the Commission as well as members of the Commission for Neuroimaging and Taskforce for Classification. Individuals with expertise from around the world in infantile seizures were also in attendance. Specific conclusions were drawn from these identifying possible key clinical questions. It is hoped that such guidelines can be taken forward during the next term of the Commission for Pediatrics although it has been made clear it is unlikely the WHO will continue to contribute.

3. Education

In 2007 the Commission was responsible for the 6th International Course on Epilepsy, 'Clinical and Therapeutic Approaches to Childhood Epilepsy' (Course Directors: H Cross and B Dalla Bernardina) held at the Venice International University San Servolo, 22 July to 3 August. This was a highly successful course involving 68 participants from 40 countries. There were 37 members of the faculty which included all but two members of the ILAE Commission for Pediatrics. The course covered all aspects of childhood epilepsy moving from diagnosis to treatment including surgery, with a high emphasis not only on lectures but also interactive working groups. The course was greatly appreciated by all those who participated.

4. Adolescent and transition of care

Over the past six months a survey has been used to determine international practice with regards to transition of care from pediatric to adult practice. A questionnaire has been distributed around all centers

and results forwarded to Doug Nordli who has led this work on behalf of the Commission. More than 60 returns have been received from over 20 countries including Europe, Asia, Mexico, USA, Canada, and Australia. We are in the process of analyzing this work to report to the Commission prior to a final meeting in July 2009, with a subsequent report to be prepared for publication and submission. It is hoped that this work be continued into the next term for the development of tools and information for adolescence and transition of care.

Recommendations for Future Work:

- 1. Guidelines for management of seizures in infancy:** It is proposed for the next term to build on work already undertaken in preparing guidelines for management of seizures in infancy;
- 2. What facilities are available at present for treatment of seizures in infancy worldwide?** In parallel to preparation of the guidelines, we recommend a survey on diagnostic facilities and treatment availability/preferences already in place worldwide, similar to what has been completed for treatment preferences in USA and Europe (Wheless et al 2005, 2007). This could act as a baseline for education and guidelines that may be developed in the future;
- 3. Adolescence and transition of care.** Following analysis of the results of the questionnaire, it is proposed that this could be used to develop tools and information that could be used globally for adolescence and transition of care;
- 4. Surgery** Extensive work has been undertaken in the surgical sub group. It is proposed that work should be ongoing with regard to a prospective international study reviewing children, pre- and post-operatively (at 12 months) who have undergone surgery, with regard to seizure outcome and cognitive progress. Funding should be sought from outside sources. With the two studies to date we have shown that the international community can work together to achieve such data and therefore should provide firmer grounding for applying for such money. A full protocol is already available;
- 5. Co-morbidities.** Contact has already been made with regard to possible work linking autism and epilepsy. A joint project is currently proposed to review where overlap may be seen, and where professional bodies may work together to enhance data collection and understanding. It would be proposed that further discussion is undertaken to outline possible project work that could take place over the next four years;

(continued on page 65)

COMMISSION ON PEDIATRICS *(continued)*

6. Collaboration with other Commissions:

Ongoing thought needs to be given as to how constructive collaboration can take place with other Commissions, to further work in developing services and management strategies.

Summary:

The work of the Commission for Pediatrics over 2005-2009 has built on international collaboration and education to raise standards of epilepsy care in children. This has included collection of epidemiological data on pediatric surgical practice and outcome, development of guidelines and organization of the San Servolo course on epilepsy in childhood. It is proposed work should continue with the development of a prospective surgical study, further guidelines and information provision, as well as projects examining comorbidities in childhood epilepsy.

References:

1. Wheless et al 2005 *J Child Neurol* 20s1:s1-6
2. Wheless et al 2007 *Epileptic Dis* 9:353-412

J Helen Cross
Chair, Commission on Pediatrics

COMMISSION ON THERAPEUTIC STRATEGIES

List of Members:

Jacqueline A French, Co-Chair (USA)
Gary Mathern, Co-Chair (USA)
Reetta Kälviäinen, Secretary (Finland)
Torbjorn Tomson, Treasurer (Sweden)
Christoph Baumgartner (Austria)
Martin J Brodie (UK)
William Harkness (UK)
Giorgio Lo Russo (Italy)
Solomon L Moshé (USA)
Emilio Perucca (Italy)
Nandan Yardi (India)

Aims:

The goal of the Therapeutic Strategies Commission is to address a wide variety of international problems in the treatment of epilepsy. Multiple Task Forces have been established to address specific issues.

Commission Activities and Accomplishments:

Task Force for Updating ILAE Guidelines and Converting to Web Format: Elinor Ben Menachem, Chair

The Task Force has accomplished two important goals. The current, accepted AED guidelines (2006) with background material in table format and PowerPoint presentation describing the guidelines has been published on the ILAE Web site. These can be found at <http://www.ilae-epilepsy.org/Visitors/Centre/AEDGuidelines.cfm>. In addition, the Task Force is near completion of an update of the guidelines, adding data up to 2008, including several important studies such as the SANAD study, and a randomized trial of levetiracetam vs. carbamazepine.

Task Force for Screening of New Antiepileptic Drugs (co-project with Commission on Neurobiology): Jacqueline French, Chair; Gary Mathern; Annamaria Vezzani; Mike Rogawski; Nico Moshé and Christophe Bernard

This Task Force was created to address the issue of whether current animal models for new therapies can predict efficacy, and whether they are optimized for finding new AEDs. The Task Force organized a consensus meeting in December 2007, attended by representatives from the clinical and research scientific communities, the NIH, and the private sectors. Excellent discussion occurred, and the concepts that emerged will be used to develop future initiatives.

Task Force for Access to AEDs (co-project with Epilepsy Care Commission): Emilio Perucca, Giuliano Avanzini and Jacqueline French

This initiative, which was initially created to address the treatment gap in sub-Saharan Africa, led to collaboration with Basic Needs, a non-government organization in Ghana. The outcome was a project

that is now under the auspices of the African Initiative of the ILAE. The project will launch with a course in Ghana in the summer of 2009, followed by an epidemiologic study of the treatment gap in Ghana, and subsequently an initiative with Basic Needs to close the gap.

Task Force for Translation of Guidelines to Clinical Practice: Reetta Kälviäinen, Chair

This sub-commission was charged with trying to provide a user-friendly, non-biased approach to treatment of epilepsy at first diagnosis. This derived from the concept that relying solely on the evidence base will, by necessity, limit the type of information that is available for evaluation. Therefore, the so-called treatment guidelines do not actually guide therapy. A plan for the project was created during this term. In essence, this project would use a Web-based tool that can gather opinion from a large number of "experts." The intent is to select 100 experts worldwide, who would be asked a number of simple questions about initial management of epilepsy with AEDs. The tool that has been selected is Zef Solutions

<http://www.zef.fi/editor/user/?d=36-24kd28ek>.

Detailed questions would be designed by a small working group, including both AES and ILAE members. After that, 100 individuals would be invited to answer using the online tool. The deliverable from this exercise would be a document that outlines the following:

- 1) Principles of care, defined as areas where there is an extremely high degree of consensus (>90%). An example might be slow initiation of lamotrigine, avoidance of valproic acid in women planning pregnancy, and avoidance of low-dose oral contraception in women receiving enzyme inducers;
- 2) Suggested strategies, defined as guidelines to initiate drugs, etc. These will not be considered as definitive, but will be agreed upon as safe, and might be used by physicians who have no personal knowledge to guide care;
- 3) Areas of controversy, defined as areas where no consensus exists. These areas can then be targeted for further scientific study.

It is hoped that this project will move forward in the next term.

Task Force on the Definition of Treatment Resistant Epilepsy: Patrick Kwan, Chair

This Task Force was formed to generate a consensus definition of treatment resistant epilepsy. The Commission felt there was a great need for such a consensus, since variance in definition was having a detrimental effect on research, and was potentially preventing patients from being referred appropriately for specialized care. After numerous telephone and face-to-face meetings, a draft has been created, that provides the following: A definition of failure of an intervention, a definition of success of an intervention,

(continued on page 67)

COMMISSION ON THERAPEUTIC STRATEGIES *(continued)*

and a definition of overall AED resistance. The document has been submitted to the ILAE EC for evaluation. In addition, there will be a session at the ILAE meeting in Budapest, and another at the AES meeting in Boston, which will present the definition in its current form, and seek opinion and discussion.

Task Force on Pediatric Surgery: Gary Mathern and J Helen Cross, Co-Chairs

This is a long-standing project in collaboration with the Pediatrics Commission. The project was aimed at determining outcome from pediatric surgeries performed at centers worldwide. Outcome data forms have been created. Twenty centers have the data form and have provided outcome data and 17 new centers, including centers from Asia and Latin America also provided data on over 1,100 patients for calendar year 2004. Initial data analysis will be presented in Budapest. It is strongly urged that this group continue into the new term to finish analysis of the dataset and return to its original goal of defining recommendations and expert consensus guidelines on the practice of pediatric epilepsy surgery. It is also hoped that this type of long standing group be formed for adult epilepsy surgery centers to undertake a survey to understand the utilization of epilepsy neurosurgery in different parts of the world.

Task Force on Surgery in the Developing World: Gary Mathern, Chair

This group initially formed and met in Singapore. It was agreed to pilot projects related to this goal using the North American Commission and Latin American Commission as examples. Progress has been slow due to lack of financial resources to develop epilepsy surgery training in Latin America. This project should move into the new term with the goal of finding ways to train individuals and develop epilepsy surgery in regions of the world where there are limited resources.

Task Force on Defining Cortical Dysplasia:

Gary Mathern, Chair

This group was formed to define the MRI and histopathological criteria of mild and severe cortical dysplasia and to address the current classification system. This group met in conjunction with the meeting on Cortical Dysplasia in Istanbul, Turkey in November 2008. Two groups were established as working groups. The first group is to further define the criteria defining cortical dysplasia and the second the MRI characteristics. Both groups continue to meet to refine their criteria. These groups should continue into the new term.

Task Force on Generics: Barry Gidal, Chair

The Task Force on generics has completed a literature search of pharmacokinetic and clinical data related to generic equivalence for major AEDs and several publications and a report are being prepared.

Task Force on Pregnancy Registries:

Torbjorn Tomson, Chair

The major Epilepsy and Pregnancy Registries have been in operation for approximately ten years, and some are beginning to release results. The question to what extent results are comparable across studies has therefore become important. The ILAE Commission on Therapeutic Strategies therefore initiated and organized a workshop on Epilepsy and Pregnancy Registry Methodologies. The meeting was sponsored by the Milken Foundation and held in Short Hills, NJ on 13-15 September 2008. The objectives of the workshop were to provide a forum for discussion of the different methods, allowing representatives of the registries to exchange information on their methodologies, and to facilitate future collaboration between them. Representatives of the three largest independent registries, the UK registry, the North American AED Pregnancy Registry (NAAPR) and EURAP participated. Important differences between the registries were highlighted and areas suitable for collaboration identified. The registries established a work group with the objective to further develop ideas of collaboration. The discussions from the workshop are summarized in a report which is intended for publication in *Epilepsia* after approval of the commission and the ILAE Executive.

Non-pharmacological Approaches Sub-commission: Nandan Yardi, Chair

There was a meeting of ILAE Non-Pharmacological Approaches sub-commission & ILAE Psychiatry Commission in Chennai, India where a half-day workshop on 'methodological aspects for Non-pharmacological interventions' was conducted, attended by members and chairs of both the sub-commissions (N Yardi, E S Krishnamoorthy). The proceedings of this meeting will be submitted to the Treatment Strategies Commission and Psychiatry Commission for approval and further action. A document which is being jointly written will be submitted before the Budapest meeting. Two articles using RCT on ACT (acceptance and commitment therapy) and Yoga from work done in the past in S Africa and India by members of this Commission (N Yardi, JoAnn Dahl and Tobias Lundgren) for the IBE Psychological Approaches Commission, were accepted and have been published in *Epilepsia* and *Epilepsy & Behavior* respectively. A list of different complementary therapies used all over the world, from different regions, has been compiled by S Schacter and N Yardi.

Recommendations for Future Work:

A. Guidelines on Web

These will continually need updating as new data emerges, and should be a permanent part of the Commission on Therapeutic Strategies.

(continued on page 68)

COMMISSION ON THERAPEUTIC STRATEGIES *(continued)*

B. Translation of guidelines to practice (Reetta Kälviäinen)

There is enthusiasm from the AES as well as many members of ILAE to pursue this project. As discussed at the Seattle meeting, this should not “dictate” treatment or identify “best therapy.” Rather, it should identify “appropriate options for initial AEDS” as more of a “practice survey.”

C. Co-projects with Epilepsy Care Commission on access to AEDs (Emilio Perucca) and Epilepsy Surgery

Basic Needs, a non-government organization, is proceeding with this project. We are expecting to have a course in Ghana in August 2009, and at that time evaluate the requirements for a demonstration project on access to medicines. This is an area that should be co-developed under the auspices of the African Agenda (under Emilio Perucca).

D. Task Force on Generics

Still a very important issue that needs future development.

E. Task Force on Pediatric Surgery

This group should continue to finish the current survey and start the prospective assessment of the value of pediatric epilepsy surgery. Also, this group should finish preparing guidelines on pediatric epilepsy surgery care.

F. Task Force on Defining Cortical Dysplasia

These two working groups should continue into the new term.

G. Task Force on Surgery in the Developing World

Should continue into the new EC term with the goal of developing working models of how to train neurologists and surgeons in regions of the world with limited resources.

H. Sub-commission on Non-Pharmacological Treatment

A project on ACT/Yoga is foreseen to be conducted by the sub-commission members in Boston (S Schachter, JoAnn Dahl, Tobias Lundgren and N Yardi) using the recommendations of methodological aspects (the stumbling block may be ethics committee approval and funding). A surrogate marker engine to determine seizure frequency has been identified by and may be used in such a study. A review of currently available RCTs and non-RCT literature in this area may also be considered.

Summary:

The Commission was able to accomplish a great deal in four years. Some projects were stand-alone, and have been completed, while others are ongoing and it is hoped will flourish under the new Commission.



Other Activities

AWARDS

2008 Morris-Coole Prize

The Morris-Coole Prize, is a new annual ILAE award that is given in recognition of an outstanding research paper published in *Epilepsia* the previous year on any field of epilepsy research, either clinical or basic.

Papers are nominated to the selection committee by the associate editors of *Epilepsia*. The prize was established to stimulate excellence in epilepsy research as well as rewarding young researchers for outstanding contributions to the field.

The 2008 Morris-Coole Prize will be awarded to **Dr. Julia Jacobs** during the 2009 International Congress in Budapest. Her paper was titled: Interictal high-frequency oscillations (80-500 Hz) are an indicator of seizure onset areas independent of spikes in the human epileptic brain. (*Epilepsia*, 49:11; 1836-1907, 2008).

2009 Michael Prize

Michael Prize, presented every two years by Stiftung Michael from Germany, this award is for outstanding epilepsy research performed by young investigators (under the age of 45).

The 2009 Michael Prize was announced during the Opening Ceremony of the 28th International Epilepsy Congress in Budapest. Recipients are **Ivan Soltesz** of the University of California, Irvine and **Chrysanthy Ikonomidou** of the Technical University of Dresden (now at the University of Wisconsin).