President’s Message

The first goal of our new Strategic Plan is the ILAE shall serve all health professionals as the premier international resource for current and emerging knowledge on epilepsy prevention, diagnosis, treatment and research. To achieve this central goal we have drawn upon our international pool of talented members, chapter leaders, and regional representatives to address the challenges and opportunities that people with epilepsy are facing.

Each Region and country has a unique history, resources and characteristics, and each Chapter faces distinct issues and challenges in developing optimal care for those afflicted with epilepsy. The League has two types of Commissions: Regional Commissions oversee issues related to a specific Region and organize educational events targeted to the specific regional needs. Task-Oriented Commissions deal with specific problems affecting people with epilepsy. These Task-Oriented Commissions help establish definitions and guidelines for diagnosis, treatment and research that help move the effectiveness of care forward. Our Commissions are working diligently to identify specific needs, and to assist Chapters in implementing their individual goals by creating effective teams and resources. These Commissions provide a critical link between the latest developments and the practitioner.

For the past several years the leadership of the League has held Annual Meetings and brought together the Commissions’ Chairs in order to promote collaborations, stimulate new research directions, as well as to establish the standards that would benefit everyone worldwide. In this issue of Epigraph we have asked the Commission Chairs to describe their achievements over the past year, and to create a blue print of the deliverables for the current term. Indeed, remarkable progress has been made thus far, and we are very pleased with the outcomes. I would like to express my sincere gratitude to all the members of the Commissions who have selflessly devoted their time. I look forward to how their efforts will provide a better world for all the people afflicted by epilepsy.

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Benefits of Chapter Membership

• The ILAE’s mission is to ensure that the 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.

• The ILAE is the international organization representing professionals working in epilepsy, and is recognized as an official partner of the World Health Organization. The ILAE works in close partnership with the International Bureau for Epilepsy (IBE), the international organization representing lay people working in epilepsy.

• The members of ILAE are epilepsy Chapters of individual countries. There is only one Chapter recognized per country.

• Membership in the ILAE requires that Chapters are representative and inclusive of the entire epilepsy professional community in that country.

• By approving a new Chapter, the ILAE endorses its legitimacy. This endorsement is important in dealing with national and international organizations and regulatory bodies.

• By becoming an ILAE Chapter:
  – Epilepsy professionals from that country gain a network of over 15,000 epilepsy professionals from over 100 different countries, organized into six different worldwide regions (Africa, Asia-Oceania, Europe, Eastern Mediterranean, Latin America and North America).
  – Chapters have access to resources allocated to Regional Commissions and activities planned in conjunction with that Region.
  – Chapters have the opportunity to engage in international collaborations in epilepsy care and education.
  – Members of ILAE Chapters have access to special rates for ILAE publications, including Epilepsia.
  – Through the work of the ILAE’s Regional and Topic-Oriented Commissions, epilepsy professionals have the opportunity to address global issues in epilepsy and to engage in initiatives in epilepsy care and education.

• Through the ILAE’s world class educational initiatives and regional / international Congresses, epilepsy professionals have the opportunity to raise the standard of epilepsy care and in their country.

• Through the ILAE member-driven Regional Commissions, epilepsy professionals have the opportunity to influence targeted action on the issues most relevant in their region, leading to improvements in local education and treatment services.

• Epilepsy professionals have access to ILAE’s coordinated efforts aimed at accessing funding for national and regional initiatives. These include improving services and access to care, combating stigma and discrimination, and fostering research and education.
An Introduction to ILAE

The ILAE is constituted as an international nonprofit organization and is registered in the United States. The ILAE is the premier international professional association of physicians and other health professionals in the field of epilepsy. It was founded in 1909 and has grown greatly in size and influence in recent years. From its earliest years, it has been organized in the form of a federation of national Chapters. Currently there are Chapters in over 100 countries and over ten thousand members worldwide.

The mission of the ILAE is to work towards a world where no person’s life is limited by epilepsy. To this end, the ILAE provides the highest quality of care and well-being for those afflicted with the condition and related seizure disorders.

Over the years, ILAE has grown in complexity and size, and it now serves a good time, briefly, to lay out its structure and component parts. For more details, readers can consult the ILAE website at www.ilae.org.

Executive Committee

The ILAE is overseen by an Executive Committee, currently of 12 persons (current members are listed below). The President (S Moshé) is elected by a ballot of national Chapters for a four-year term. The Secretary-General (S Wiebe), Treasurer (G Tan) and three Vice Presidents (J Tomson, M Bialer, and M Medina) are also elected by a ballot of national Chapters for a four-year term. The Information Officer (B Tomson) and the Editor-in-Chief of Epilepsia (P Schwartzkroin, S Shorvon) are appointed by the President and the Executive Committee. The Past President (P Wolf) serves for a four-year term. The Past President (M Glyn), Secretary-General (C Acemede) and Treasurer (G Tan) of the sister organization, the International Bureau for Epilepsy (IBE), are ex-officio members of the Executive Committee.

Constitution and Bylaws

The ILAE is governed by a written Constitution and Bylaws, and these are posted on the ILAE website. The Constitution has fifteen articles, and the Bylaws have fifteen sections, and these cover the objectives, membership, governance and the range of the ILAE activities and its structure. The Constitution can be amended at the General Assembly of the ILAE. There is a standing Constitutional and Elections Task Force to oversee changes in the Constitution. The Constitution and Bylaws were updated in 2011.

Chapters

Each national Chapter has its own Constitution on Bylaws and its own President and officers, elected by individual members of each Chapter. The constitutional and leadership arrangements vary from Chapter to Chapter, within stipulations defined in the ILAE Constitution, as do the details of membership eligibility. However, generally speaking, membership is open to any doctor and health professional interested in epilepsy.

There are currently 109 Chapters in the ILAE, which is the greatest number in its history. National Chapters range in size from 3,000 to just seven voting members. The role of the national Chapters is generally to establish and maintain good communication between persons active in the field of epilepsy, assist in the care of epilepsy and maintain standards of this care in their own countries, promote publications in the field of epilepsy, organize or sponsor national meetings, appoint Commissions or individuals for specific problems, and develop or apply other methods for the furtherance of the objectives of the ILAE.

Regional Bodies

ILAE is also divided into six Regions (North America, Latin America, Europe, Eastern Mediterranean, Asia and Oceanian, and Africa). Each Region is made up of a grouping of national Chapters — the largest is Europe with 46 Chapters and the smallest is North America with three national Chapters. Fully developed Regions each have a Regional Commission and a Regional Council, and regional scientific conferences are held every two years. Active Regions also conduct research and education and have a role in influencing public policy in epilepsy at a regional level. The currently constituted Regional Commissions are: African Commission (Chair – A Beydoun), European Commission (Chair – M Hirsch), Asian and Oceanian Commission (Chair – S Lee), North American Commission (Chair – S Hur), Latin American Commission (Chair – M Campos), Eastern Mediterranean Commission (Chair – A Beydoun).

Commissions and Task Forces

In every four-year term, the President and the Executive Committee appoint Commissions and Task Forces, to carry out work for the ILAE. These bodies include individual members transnationally. Currently, the following Topic Oriented Commissions and Task Forces are constituted: Classification and Terminology (Chair – I Scheffer), Conflict of Interest Task Force (Chair – P Wolf), Constitution Task Force (Chair – T Tomson), Diagnostic Methods (Chair – F Cendes), Education (Chair – C Tatsch), Ethics Commission (Chair – P Wolf), Epidemiology of Epilepsy (Co-Chair – B Hirschfeld and E Beigh), Epilepsy in Pregnancy Committee (Chair – E Penry), Genetics of Epilepsy (Chair – S Barkana), Global Campaign (Ex-Chair – B Susanna and M Sperling), Past President Advisory Council (Chair – G Aurness), Pediatrics (Co-Chairs – D Hardin and P Piraino), Strategic Planning Task Force (Chair – G Mathern), Therapeutic Strategies (Co-Chair – B Sternhall and S Schadlen)...

Staff

The ILAE is administered by a full-time professional staff based in Dublin, Ireland. The staff is divided into the following groups: Publications Coordinator; Deborah Flower, Manager; Cheryl-Ann Tubby, IOM, and Website Manager; Cynthia Hesdorffer, IOM. IRCD provides services to its 109 Chapters from its headquarters in Dublin, Ireland, and currently is published monthly. It has a subscription base of 7,769 (corporate, individual and institutional), and, in 2011, 779,641 articles were downloaded from its online hosts.

Global Outreach

This is a joint ILAE, IBE and WHO initiative, launched in 1997. The first phase of the Global Campaign Against Epilepsy was launched in 2001 and was devoted primarily to activities that promote public and professional education about epilepsy, identify the needs of people with epilepsy on a national and regional basis, and encourage governments and departments of health to address the needs of people with epilepsy. The second phase of the Global Campaign Against Epilepsy was launched in 2005 and is focused on special projects in different parts of the world and an assisting healthcare authorities worldwide in the field of epilepsy.

Epilepsia

Epilepsia is the scientific journal of the ILAE and the leading journal in the field of epilepsy. It is published by Wiley-Blackwell and edited by an Editor-in-Chief (or, as currently, two Editors-in-Chief: P Schwartzkroin, S Shorvon) who also appoint an editorial board and Associate Editors (currently: P Wolf, B Hirschfeld, G Tan, E Bertram, P Berkovic, S Berkovic, M Mula), Past President Advisory Council (Chair – G Aurness), Pediatrics (Co-Chairs – D Hardin and P Piraino), Strategic Planning Task Force (Chair – G Mathern), Therapeutic Strategies (Co-Chair – B Sternhall and S Schadlen).
ILAE Chapters

An Introduction to ILAE

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Finances

With the assistance of the Financial Office, ILAE finances are overseen by Emilio Perucca, Treasurer, who reports to the Executive Committee on all financial matters. The current Executive Committee has adopted a policy committing three percent of the investment portfolio to underwriting new projects and programs emphasizing education, epilepsy care and translational research.

Membership of the Executive Committee, regional bodies, Commissions and Task Forces is honorary and members are not paid for their work. The editorships of Epilepsia and Epigraph are also unpaid. Salaried staff is located in three administrative offices: Headquarters Office located in Hartford, Connecticut, USA; Chapter Services Office located in Dublin, Ireland; and the Meeting Planning Office located in Dublin, Ireland.

Income is derived from national Chapter dues, sponsorship, Epilepsia royalties, international and regional Congresses, and investment income. The annual dues of each Chapter to ILAE are a minimum of $10 per year per Chapter, except for countries with low GDPs (World Bank categories low and lower middle) for whom membership is supported by a solidarity fund.
An Update from the Treasurer on the Finances

The Treasurer’s mandate is to: secure and diversify the League’s main sources of income; ensure the income and expenses are in line with our goals and aims; ensure high professional standards in terms of financial management and internal control; reduce the organization’s fixed costs, including streamlining our various administrative offices; and monitor ILAE’s financial business plan, reserve policy, and investment portfolio.

Over the past couple years, League assets have increased due to recovering investment gains after the economic crisis of 2009, reducing administrative costs by 30 percent and negotiating a favorable contract with the publishers of Epilepsia. New Committees have been put into effect to oversee the financial operations. A Budget Review Committee including colleagues from all regions of the world was created to assist the League’s Finance Committee and the Executive Committee in evaluating projects and budget applications from each of the League’s Commissions. In addition, a Finance Advisory Subcommittee was established to assist the Finance Committee and the Executive Committee in ensuring that our investment policy is optimally adjusted to address the League’s mission. The Advisory Subcommittee also assists the Treasurer and the Financial Manager in monitoring the day-to-day performance of the League’s investments.

The year 2010 was exceptional in terms of revenue, due to A) receipt of a one-time $500,000 signing bonus for renewing our contract with the Epilepsia publisher, B) a peak surplus from Congresses (which typically show high variation in surplus from one year to the next), and C) high return from investments related to a striking rebound in financial markets. For 2011, projected revenue is conservatively expected to be about 40 percent lower than 2010. Between 2010 and 2011, we also substantially increased our expenditures to support the expanding activities of our Commissions and a wide range of educational projects.

Globally speaking, these are financially challenging times. In addition to anticipated revenue decline, we must also be aware of market volatility and threats of inflation. We are very fortunate to have expert advice to help us navigate through these troubling times. For the remainder of my term, we will continue to assess and evaluate our policies to ensure that ILAE will now and in the future have the financial means to continue the fight against epilepsy worldwide.

2009-2013 Executive Committee

President
Solomon L. Moshé

Secretary-General
Samuel Wiebe

Treasurer
Emilio Perucca

Past President
Peter Wolf

1st Vice President
Tatsuya Tanaka

2nd Vice President
Michel Baulac

3rd Vice President
Marco T Medina

Epilepsia
Editor-in-Chief
Phil Schwartzkroin

Epilepsia
Editor-in-Chief
Simon Shorvon

Information Officer
Edward Bertram

IBE President
Mike Glynn

IBE Secretary-General
Carlos Acedo

IBE Treasurer
Grace Tan
Global Outreach

The IAE / IBE / WHO Global Campaign Against Epilepsy (GCAE) has as its mission statement: To improve acceptability, treatment, services and prevention of epilepsy worldwide. The ultimate goal of the Campaign is to close the treatment gap in epilepsy. To date over 100 countries have developed activities under the Campaign.

In 2009, a task force was created with the aim of establishing a Strategic Plan with action points to broaden wider development of activities within the GCAE, and to assess the status of achievements. A Strategic Plan was finalized, with four main goals by which certain progress within the GCAE could be achieved over a four-year period:

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

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

Regional activities

Strategic Plan for Epilepsy

During 2011, a strategic epilepsy plan was developed for the Americas involving stakeholders in the Latin American Region, IBE and ILAE Presidents, representatives of the Global Campaign and of the Pan American Health Organization (PAHO). The regional leadership of PAHO, which involves Ministries of Health of all the member states, are to include epilepsy as a health priority for the next 10 years. The Strategic Plan was approved on 29 September 2011 by the Ministers of the Health Council of the Americas in Washington, during their Annual Meeting. The plan will lead to the establishment of all countries in the region to develop, based on the national realities, a national plan for epilepsy. This epilepsy plan is now included in Americas Government Health Priorities. All countries will be obliged to submit an annual progress report to WHO / IBE / IAE. This document may be a model which can be used in the other regions of the world.

In October the Strategic Plan was launched in Tegucigalpa, the capital of Honduras. The entire process was initiated under the auspices of the Global Campaign Against Epilepsy.

WHO Declaration on Epilepsy

A Joint Task Force of IAE and IBE, and the Alzheimer’s Alliance (AAL), was established, to facilitate initiatives that enhance public awareness and support to epilepsy research in Europe. EAE seeks to raise epilepsy priority in political and research establishments across Europe. The first initiative of this Task Force was the establishment of an European Epilepsy Day, which was launched on 14 February 2011 in the European Parliament in Strasbourg, France. A special working group of Members of European Parliament (MEPs) with an interest in epilepsy was formed and their first action was to support approval of a WHO Declaration on Epilepsy. This was a major project as it required a minimum of 369 signatures of MEPs collected within three months. At the deadline a total of 659 MEPs had signed and the Declaration was passed on 15 September 2011. The Declaration is a very important document to use at national and EU level, for advocating for increased research funding, advocating for improved healthcare facilities and services provision for people with epilepsy, and for building other significant initiatives at the European level.

Assessment of Country Needs and Resources on Epilepsy

In early 2011, a project to conduct a needs and resource assessment specific to epilepsy in Tajikistan was initiated by IGE in collaboration with the WHO European Regional Office, and the WHO Country Office Tajikistan. A standardized data collection instrument was created, building on other related collection tools and reports, such as the data collection survey used for the WHO Epilepsy Atlas 2005, the WHO tool for mental health priorities (WHO, IAE / ILAE 2005, “A Guidelines on Violence Prevention: Human Rights and World Federation of Neurology Survey on Neurology Education and Training.

For data collection, the WHO Country Office identified a group of stakeholders who implemented the tool and provided the responses to questionnaires. Interpretation of the data collected is being completed and the next steps of this project involve preparation of a country report that would help integrate epilepsy diagnosis and treatment into primary care in Tajikistan as well as be used as the basis for a demonstration project. A project has now been proposed to IBE and IAE to improve and replicate the administration of the epilepsy need and resource assessment instrument in two European countries over the next two years.

Demonstration Projects

The general objective of Demonstration Projects are to reduce the treatment gap and the social and physical burden of epilepsy, educate health personnel, and shape attitudes. Demonstration projects have been completed in Senegal, Zimbabwe, Brazil and China. The ultimate goal is to develop a variety of successful models of epilepsy control that will be integrated into the healthcare systems of the participating countries and Regions, and, finally, applied on a global level. Demonstration Projects are being finalized in Georgia and have been initiated in Honduras while the means are being sought to also initiate one in Cameroon.

In October of this year a seminar / workshop was organized to evaluate the consequences of the project for epilepsy care in Georgia. The workshop and symposium were held in Tbilisi, Georgia. The event marked the official closure of the IAE / IBE / WHO Global Campaign Against Epilepsy Demonstration Project on Epilepsy in Georgia. Reports on all projects were presented, their consequences, outcome assessment and lessons learned. A full report on this workshop will appear shortly.

Project on the burden of epilepsy

The Global Burden of Disease, Injuries, and Risk Factors Study (GBD) (1990–2008) provides a complete systematic assessment of the data on all diseases and injuries. Within a new GBD project, comprehensive estimates of the burden of epilepsy, it is disabling sequela and its role as a risk factor for other diseases and injuries will be developed.

Specific aims:

1. To generate comprehensive estimates of the burden of disease due to idiopathic epilepsy.
2. To generate comprehensive estimates of the burden of disease due to epilepsy.
3. To generate comprehensive estimates of the mortality and burden of disease due to epilepsy.

The Global Campaign Against Epilepsy continues to contribute to the above process.

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

An algorithm was developed for diagnosis and treatment of essential seizures especially in resource-limited settings, aiming at clinicians in developing countries in collaboration with the WHO Department of Child and Adolescent Health and Development and published in Epilepsia. The Guidelines will be published shortly.

Project on Legislation

The results of this project will be useful for policy makers, health planners, administrators, legislators, lawyers, health professionals and patient groups at a national, regional as well as international level. A document on the subject has been developed and is ready for publication. Even during its execution the project served as a source of information and offered support to IBE / IAE members involved in the development of anti-discriminatory legislation in connection with epilepsy. For instance the Campaign coordinator and others have been instrumental in the development and appraisal process of a law for the protection of the rights of people with epilepsy in Colombia, which was signed by the President.

mhGAP Forum

In all countries throughout the world, there is a wide gap between the high prevalence of mental, neurological and substance use disorders and the low proportion of affected individuals that receive adequate care. This gap is particularly wide in low- and middle-income countries. To assist Member States in addressing this gap, WHO launched the mental health Gap Action Program (mhGAP) in 2008. A technical assistance program aimed at supporting Member States in scaling up care for priority mental health conditions, within the

(continued on page 6)
The Special Partnership Between ILAE and IBE

Mike Glynn, President, International Bureau for Epilepsy

The partnership forged between the International League Against Epilepsy and the International Bureau for Epilepsy was further reinvigorated during 2011, IBE’s 50th year. This year saw the convening to fruition of the Joint Task Force for European Advocacy in Europe (EAE), a collaboration between IBE and ILAE designed to improve healthcare and research in the Region while also reducing stigma. The very first European Epilepsy Day (EED) was held across Europe on 14 February 2011 with landmark events held at the European Parliament in Strasbourg. There the leadership held meetings with EU Commissioners and Members of European Parliament (MEPs) and held several major events to promote epilepsy awareness.

The first EED helped the push to have a landmark European Declaration against Epilepsy signed by a majority of MEPs so that it could be written into the record of the European Parliament and so that Health Ministers throughout the EU would be notified. After a great deal of effort this was achieved in September. This will now provide the platform for the EAE to push ahead with its efforts to make politicians and the general public in Europe aware of all that needs to be done.

The "mhGAP Forum" is an informal and evolving group of Member States, intergovernmental and non-governmental organizations, including UN Agencies, international development agencies, philanthropic foundations, research institutes, universities and WHO Collaborating Centres. In October of this year the 3rd meeting of the mhGAP Forum took place in Geneva. Emilio Perucca, Mike Glynn and Hanneke de Boer participated as representatives for the world of epilepsy. One of the sessions of this meeting focused on learning from the experiences of a wide variety of organizations and experts working in low- and middle-income countries. The mhGAP is being implemented by WHO in collaboration with a large number of partners. These include governments, civil society including NGOs, professional associations, academic institutions including WHO Collaborating Centres and others. This session illustrated and highlighted some of these contributions. Partners briefly described their activities with the objective of making others aware and contributed to identifying factors that lead to success and failure in scaling up services for priority conditions. Both Mike Glynn and Emilio Perucca were invited to present a brief report on various aspects of the work of IBE and ILAE and highlighted respectively the successful activities in EURO and AMRO.

Hanneke M. de Boer
Helen Cooz
Shichuo Li

Endnotes

1. In 1997 the ILAE, IBE and WHO joined together to launch the Global Campaign Against Epilepsy: "Epilepsy Out of the Shadows". The objective of the Global Campaign is "To improve the acceptability, treatment, services and prevention of epilepsy worldwide." The Demonstration Projects initiated by the Global Campaign are to improve accessibility to epilepsy care in the developing countries. A Demonstration Project illustrates good practice in providing services to people with epilepsy and will be used as a model of what can be achieved.

Global Outreach

(continued from page 5)

WHO, The World Health Organization, leading international public health agency ILAE: The International League Against Epilepsy; representing medical professionals IBE: The International Bureau for Epilepsy; on behalf of people with epilepsy and their families, non-medical professionals and the general public

How to Apply for Chapter Membership

The ILAE is a federation of over 109 Chapters and a person can join the ILAE by becoming a member of their Chapter. Benefits of membership of a Chapter include:
• Full participation in national and international activities of ILAE
• Chapter conferences and other benefits of individual Chapters
• Eligibility for membership of ILAE Commission/Task Forces

Individual Chapters vary in exact criteria for membership, but generally speaking, any doctor or health professional with an interest in epilepsy is eligible for membership. To join, write to the Secretary of your Chapter. You can find the contact addresses on the ILAE website at www.ilae.org.

Your membership in the International League Against Epilepsy is vital. Of greatest importance is the fact that membership strengthens the authority of ILAE in its mission to influence and improve epilepsy care worldwide. Your membership counts, because part of the League!
Topic-Oriented Commission Reports

A Report from the Commission on Epidemiology

Dale C Hesdorffer, MD and Ettore Beghi, MD, Co-Chairs

The Commission on Epidemiology was established in 2009. Co-Chairs are Dale C Hesdorffer (New York, USA) and Ettore Beghi (Milano, Italy).

Commission members include Allen Houser (Past Chair), Lay Snyder (Treasurer), Charles Newton (Secretary), Toshikazu Tanao (Educational Officer), Giancarlo Logroscino (Information Officer), Ding Ding, and Marco Medina (Executive Committee Liaison).

The Epidemiology Commission softs for this term reflect the goals of epidemiology and include the following activities of the previous Commissions from 2000-2003. These goals are being accomplished in collaboration with other ILAE Commissions (Classification, Diagnostic Methods, Education, Pediatrics, and Psychobiology). Within this framework, the action plan of the Epidemiology Commission for the 2009-2013 terms includes the following activities.

The Commission completed a position paper outlining standard definitions, study designs, and instruments to improve the quality of epidemiological research on epilepsy and to facilitate comparison of the burden of epilepsy worldwide (Thurman et al, 2011). The Commission is now trying to set up workshops at meetings to disseminate the information in this report to those interested in epidemiological studies of epilepsy.

The Mortality Task Force is engaged in work on prevention of epilepsy-related deaths. To this end, we have completed a pooled analysis of the available evidence on the risk factors for sudden unexplained death (SUDEP). Two articles have been published on the results of this work (Hesdorffer et al, 2011 & 2012). The first analysis, risk factors for SUDEP included an increased frequency of generalized tonic-clonic seizures (GTCS), use of polytherapy, duration of epilepsy, young age at onset, gender, symptomatic etiology, and magnesium therapy. The second analysis focused on whether GTCS frequency, polytherapy, or number of drugs were associated with an increased risk for SUDEP and found that after adjustment for individual drugs or number of drugs, only GTCS frequency was associated with an increased SUDEP risk. AEDs were not associated with increased risk. The Task Force is currently engaged in a review of causes of death in epilepsy with a focus on preventable causes where there is potential for prevention strategies to reduce the burden of preventable mortality in epilepsy.

The Comorbidity Task Force is working on a review to determine and describe the scope of epilepsy comorbidities (psychiatric, neurological, other somatic and cognitive); clarify whenever possible the time order of associations; determine the impact of comorbidities on the prognosis of epilepsy; and determine which if any comorbidities are specific to epilepsy.

The Reliability Task Force is evaluating the reliability of the classification of epilepsy according to ICD-10, ICD-11 and the NIH consensus forms for seizure type and etiology. Seventy-one case reports have been created covering children and adults. These will be presented three times with increasing information to mirror what may be found in different clinical settings.

The Status Epilepticus Task Force is developing a definition of Status Epilepticus for use in epidemiological studies.

Task Force members: Marcio Th, Giancarlo Logroscino and David Thomson (Co-Chairs) Dale Hesdorffer, Ettore Beghi, Allen Houser, Lay Snyder, Charles Newton and Toshikazu Tanao

References


Commission on Neuropsychobiology

Aniela M Kanner, MD and Marco Malu, MD PhD, Co-Chairs

Co-Chairs: Andrea Kanner (IFS), Marco Malu (Italy)

Members: Mike Kerr (UK), ES Krishnamoorthy (India), Frank Bercy (IOH), Thorne Schimitz (Germany), W. Carl LaFrance Jr. (USA), Ulisse Nunez Oranco (Mexico), Monte Adams (Japan)

The mission of this Commission is to ensure that health professionals, patients and their care providers have the educational and scientific resources that are essential in understanding, diagnosing and treating psychiatric and cognitive complications in patients with epilepsy. One of the principal aims is to provide clinicians (neuropsychiatrists and non-neurologists alike) with practical and user-friendly tools to identify psychiatric and cognitive comorbidities in epilepsy and to provide clinicians with a pragmatic approach to the treatment of these psychiatric comorbidities.

Regarding diagnosis the Commission is working on the translation and validation processes of screening instruments for psychiatric disorders in epilepsy. The Neuropsychiatric Diagnostic Inventory for Epilepsy (NDI-E) is now available in English, Spanish, Portuguese, French, German and Italian. The Commission is in touch with key members of local Chapters in Asia for the Japanese and Chinese versions. In conjunction with the Task Force on Psychiatric Aspects of the American Epilepsy Society, a screening instrument for suicidality in epilepsy has been developed and it is being tested in a small group of patients for feasibility. The Task Force on Childhood Neuropsychiatry has identified a number of screening instruments for psychopathology in children with epilepsy with special attention to depression, anxiety, hyperactivity, attention problems, and conduct disorder spectrum (CHADS). Results of feasibility in a test sample are almost ready and a preliminary draft of the document is in preparation.

Regarding treatment strategies, the Commission is working on the development of a pragmatic approach to psychiatric comorbidity. A special issue of Epilepsia will be dedicated to this issue providing a very practical and user-friendly guide for the pharmacologic and non-pharmacologic treatments of major psychiatric disorders affecting adult patients with epilepsy as well as special populations such as cognitively impaired subjects.

A special focus of the Commission is related to the burden, mortality / life expectancy, hospitalization and access to care of people with epilepsy and intellectual disabilities. In conjunction with the IBE, a Web-based survey explored the views of health professionals involved in the care of these patients in order to develop future projects focused on specific needs. Results of this project will be soon available in a special document.

Finally, the Commission is aware that new generations of antiepileptic drugs and behavioral care professionals involved in the epilepsy setting need to be specifically trained in the management of psychiatric and cognitive complications of epilepsy. The Task Force on Education has developed a special educational VIREPA module on psychiatric comorbidity of epilepsy that is going to start in 2012.

(continued on page 8)
A Report from the Commission on Genetics

Sam Berkovic, Chair

The Commission on Genetics has three central aims, and significant progress has been achieved in the last 12 months.

Aim 1. To improve the genetic literacy of members of the League to ensure up-to-date information can be provided in their professional roles.

There is an exponential explosion in the amount of information regarding genetics and it is difficult for even experts to keep up. Our critical task is to try and make the constant flow of information available and accessible in a meaningful way to practicing clinicians and researchers. We have four initiatives to help achieve this aim.

First, the Commission has maintained the "epiGAD" website which has a comprehensive listing of genetic association studies in epilepsy. This is largely for the use of the research community and is actively used. Second, there is our user-friendly, authoritative source for genetic information in epilepsy on the web. Genetic counselors must often turn to an excellent website "GeneTests" but the representation of epilepsy on this is incomplete and needs better organization. The Commission has been negotiating with GeneTests and we will work with them to try and develop a comprehensive web presence. Third, the most important pragmatic test at the moment in epilepsy genetics is testing for changes in the neuronal sodium channel SCN1A. A Commission report is in the final stages of development for publication on this. Fourth, the Commission is encouraging the ongoing VIREPA course on genetics which has been successful.

Aim 2. To develop information sources regarding genetics of epilepsy for the public, taking into account regional sensitivities, cultural factors and possible stigmatization related to epilepsy and genetics.

Public perceptions, information and, importantly, misinformation about genetics are essential issues that are challenging to deal with in the public domain.

We are developing a document for public education in epilepsy and this will need careful handling in terms of its international applicability in different countries, languages and cultures. We are working with the Global Campaign and the IBE to try to effect this.

Aim 3. The third aim is to assist in coordination of international efforts to understand the basic of complex epilepsies.

The field of genetic association studies has exploded in the last few years due to technological advances. To date, there have only been two published studies in epilepsy with essentially negative results. This is likely due to relatively small sample sizes. The Commission has facilitated the formation of the IBA Consortium on Genetics of Complex Epilepsies. A Charter has been developed and groups with large numbers of genotyped samples from Europe, UK, USA, Japan, Hong Kong and Australia have joined and we would welcome any other participants. The Consortium has met twice so far and teleconferences. A major meeting will be held on March 27 in London under the auspices of the Commission. It is hoped that this will lead to major research advances and understanding the genetic determinants of the common epilepsies.

ILAE Neurobiology Commission

Astral Nehlig (Strasbourg) and Jeffrey Noebels (Houston), Co-Chairs

The Neurobiology Commission is actively involved in planning and implementing international educational projects designed to train young neuroscientists entering the field of basic and translational epilepsy research. In the current year, these include support of the 3rd Brainstorm Garden Conference on Epilepsy to be held in New Hampshire, USA (August 2012), and scientific symposia at the European Epilepsy Congress (EEC) in London (October 2012).

The Gordon Conference on Mechanisms of Epilepsy and Neuronal Synchronization will present cutting edge research on the theme of functional reorganization in the epileptic brain. The issues will be addressed at multiple levels, from cellular and molecular to circuits and networks. The focus will be on three important and persistent questions in the epilepsy field. What are the mechanisms underlying acute seizures? What progressive changes in brain organization and function lead to the chronic condition of epilepsy? What are the relationships between the mechanisms of epilepsy and the complications that are frequently encountered in this disorder? These questions will be considered specifically in sessions devoted to epileptogenesis, seizure generation, and developmental epilepsies, and their complications. An international faculty of young investigators will be supported by the ILAE Neurobiology Commission.

This year, a newly-created Task Force on Translational Research, directed by Terence O'Brien (Melbourne) and Co-Chaired by Michele Simonato (Ferrara), is developing a comprehensive set of criteria to standardize preclinical analysis of new antiepileptic therapies. The need for more stringent preclinical analysis was highlighted by NHIBS Director Dr Stanny Lands at a recent NIH epilepsy workshop on antiepileptic drugs, who emphasized that the NIH investment in human clinical trials could be accelerated by a higher quality of preclinical evidence. As a result, a multidisciplinary group of experts in epilepsy drug development, animal models, and human clinical AED tests will assemble a report entitled "ILAE Recommendations for Preclinical Epilepsy Drug Discovery Models, Designs, Best Practices and Standardization." The ILAE Task Force will meet collaboratively with the AES Translational Task Force to forge this document at a two-day workshop preceding the London EEC.

A second major program directed by the Commission is the advanced Workshop on Neurobiology of Epilepsy (WONOEP). Last year, the 11th WONOEP was held in Gubbio, Italy in August. The topic of this workshop, directed by Marco DeCarli and Andrew Vezina (Milan) and the Commission Chairs, was "Finding Novel Mechanisms for Epilepsy Therapy." The workshop was structured in panel sessions on the following sub-themes: Receptors / ion channels and synaptic transmission; Anti-inflammatory strategies; Metabolic homeostasis; Drugs aimed at neurodegenerative targets for epileptogenesis, and Strategies for Preclinical Screening and Pilot Design. These sessions are being summarized in a series of "Critical Appraisals" for publication this year in Epilepsia.

A new project entitled "From Professional Training in Neurobiology to Regional Research Funding," proposed by the Educational Task Force of the Neurobiology Commission is under development with the Educational Commission. The joint project seeks to advance professional training in epilepsy with a focus on new research projects designed to solve regional epilepsy issues in less advantaged countries. The initiative will begin by identifying specific topics with clinical and social regional relevance, local human resources and institutional structures that can perform and host the research activities, forming an international support network, and developing local and international funding to support the project.

Other activities supported by the Neurobiology Commission for 2012-14 included the organization of sessions for the ILAE Congress in Montréal and the associated WONOEP Workshop. In addition, the Commission will support the 9th Advanced International Course: Bridging Basic with Clinical Epileptology-4, which will be held in San Sebastian, Vizcaya. This unique residential course brings together young clinical and basic epileptologists for an intensive two-week collaborative experience in designing translational research projects under the guidance of leaders in the field.

Education Commission

CT Tan, Chair

Mission and aims

The role of the Education Commission is to coordinate the education efforts by the various Regional Academies and Topic-Oriented Commissions, and to be directly responsible for the online educational activities.
The Regional Academies and Commissions

The ASEPA, EUROPA, AJADE, North America, Eastern Mediterranean, continue with their various efforts in education. The African Commission was formed in 2010. There are various education activities being carried out in the different regions. They are summarized as follows:

1. Workshops and summer schools:
   - There were nine stand-alone workshops organized by ASEPA in 2011. Various education programs were also conducted during the WEC in Rome. The Neuroanatomy Commission organized the 11th WONCAP in Gentrotta. As for the longer duration training courses, other than Edat in September, a summer school was successfully held for the first time in China in Chengdu – the gateway city to West China.
2. Visiting professorships:
   - This is mainly by the North American Commission with emphasis on building of long lasting academic and clinical relationship between centers in Latin America, the Caribbean and North America. There is plan to extend this scheme to Africa in 2012.
3. ESG Certification:
   - This is mainly by the ASEPA, conducting a two part ESG certification examination.
   - There are six each of Part I and Part II examinations being conducted in various parts of Asia in 2011. To date, there are 304 candidates who have taken the Part I examination with a passing rate of 63 percent, and 138 candidates in Part II with a passing rate of 62 percent.
4. Fellowships:
   - This is run by the ASEPA and Latam Commission. To ASEPA, this was started in 2003. By the end of 2010, there were 34 candidates who have benefited from the program. Other than one candidate, the others have all returned to serve in their own communities. Many of the fellows are now in leadership positions in the various national chapters.
5. Publications:
   - The proceedings for the Melbourne ADEC in 2010 was published in May 2011, with the online version under open access on ILAE website.
6. Research mentorship and grant:
   - The Neuroanatomy Commission is planning to build on the residential courses with hands-on tutoring of practical research proposals that are likely to create an impact in resource-poor regions, including guidance to grant applications from 2012. The proposal also includes providing a seed grant and mentoring all implementation and progress.

Distance Learning Courses:

The League satisfied the organizational and financial stability of the long distance education program by acquiring direct control and investing in the expansion of the Virtual Epilepsy Academy (VEPA) and by creating a Task Force on Distance Education led by Walter van Emde Boas within the Education Commission. It is organizing and conducting the various teaching courses with the Regional Academies and Topic Oriented Commissions. In order to increase the attractiveness and accessibility, ongoing courses have been shortened and either divided in basic and advanced parts (Imaging and Pharmacotherapy) or split in a general course (ESG) to which new a totally new course on pediatric EEG & Epilepsy has been added. The course on Genetics is being remodelled along the same line. For 2012-2013 new courses on Psychiatric Aspects and on Sleep and Epilepsy are in development.

E-Textbook:

This project is under Shih Hui Lim as the Editor. The Editors for various sessions have also been appointed. About 50-100 common topics will form the first edition. Hopefully we can keep the timeline of uploading the first edition in 2012. There is also a plan to translate the textbook into Spanish and Chinese.

Recorded Presentations:

In addition to the workshops in Melbourne ADEC, some of the education sessions in Rome IEC were also recorded. These recaptured voice-power point slides are being uploaded to the “recorded presentations” section of the of the ILAE website. Similar recapturing of the presentations are being prepared for the various Regional Congresses in 2012.

Therapeutic Strategies Commission

Steve Schachter, Bernhard Steinhoff, Co-Chairs

The mission of the Therapeutic Strategies Commission is to improve the care of patients with epilepsy by facilitating collaboration among clinicians, scientists, and other professionals in fulfillment of the relevant aspects of the ILAE strategic plan. The Commission pursues its mission in several key therapy-related areas: behavioral treatments, drugs, natural products, new methods for clinical therapeutic studies, pharmacogenomics, surgery and the global treatment gap through Task Forces.

- **Natural Products**: Recognizing the need for reliable information to guide neuroscientists interested in studying natural products as potential treatments for epilepsy, Task Force Chair, Steve Schachter, has guided the development of an extensive and unique Wiki that encompasses the historical, botanical, scientific and medical aspects of plant-derived products, which should soon be installed on the ILAE server.
- **New Strategies of Clinical Therapeutic Studies**: Task Force Chair, Jacqueline French, coordinated a meeting between the EFAA and FDA in Paris in November 2011 to discuss the concept of eliminating the need for a monotherapy index for epilepsy, as well as acceptance of a novel trial design (time to event).
- **Pharmacogenomics**: Task Force Chair, Patrick Kwan, has organized several Task Force meetings to discuss the definitions of epilepsy phenotypes, which is a critically important first step in designing pharmacogenomics studies.
- **Treatment Gap**: Task Force Chair, Hanneke De Beer, is coordinating efforts across ILAE to address the global treatment gap. Activities include 1). Revisiting the definition of the treatment gap and 2). Addressing the barriers to widespread use of pharmacotherapy in resource-poor countries.
- **Surveys**: Task Force Chair, Bernhard Steinhoff, convened meetings in Rome to define a consensus approach to surgical treatment of common epilepsy syndromes and to develop guidelines regarding minimal standards for presurgical workup and surgical treatment of epilepsy.
- **Behavioral Treatments**: Under the leadership of Jalal Dhal, the Behavioral Treatments Task Force intends to actively explore opportunities to test the feasibility and preliminary benefits of a behavioral approach to epilepsy treatment in a developing region. In this regard, a potential collaboration with Guangzhou Children’s Hospital in Guangdong, China, to study Acceptance and Commitment Therapy for children with epilepsy is under consideration.

Commission on Diagnostic Methods

Fernando Cendes, Chair

In conjunction with the Education Commission, the Commission on Diagnostic Methods is supporting the planning and implementing of e-learning imaging and ESG courses, as well as other educational activities in different parts of the world, such as in activities during Regional Congresses and Latin American School of Epilepsy (LASEE). The work of the five task forces under this commission can be summarized as follows:

- **Focal Cortical Dysplasias (FDC) Taskforce**: After a long discussion, a proposal for a new neuropathological classification system for FCD was published in *Epilepsia* in 2011, and now is working on the validation and imaging correlation of this proposal.
- **Neuropathology Task Force**: The Neuropathology Task Force is working on a proposal for a semi-quantitative ILAE scoring system for HS in patients with TLE.

(continued on page 11)
Entry criteria

I. Pharmacology

EEG

The course will cover the basic elements of the practice of EEG in its application to the diagnostic work up and the management of persons with suspected or already established epilepsy, adults and children.

Course Directors: Dr W van Emde Boas, Dr S Beniczky

Duration: 10 learning units of 2–3 weeks each and 1 week for final task

Course fee: 1000 Euro. Self payment for approved bursaries will be 250 Euro

II. Management of Epilepsy in neonates & children

The course will cover the basic elements of the practice of EEG in its application to the diagnostic work up and the management of children with suspected or already established epilepsy.

Course Director: Dr P Flouin

Duration: 8 learning units of 2 weeks each and 1 week for final task

Course fee: 900 Euro. Self payment for approved bursaries will be 225 Euro

III. EEG SCORE Course

SCORE is a computer-based system for EEG interpretation and recording based on a pan-European consensus endorsed by the CEA-ILAE and the European Chapter of IFCN. This course will cover the main elements of SCORE: personal data of the patient, referral data, recording conditions, background activity, sleep and drowsiness, non-ictal findings, "events" (ictal findings), normal variants and patterns, artefacts, polygraphic channels, interpretation and diagnostic significance. Specific aspects of the neonatal EEGs are scored: alertness, temporal organization and spatial organization.

Course Director: Dr S Beniczky

Duration: 6 learning units of 2 weeks each and 1 week for final task

Course fee: 600 Euro. Self payment for approved bursaries will be 150 Euro

IV. Genetics of Epilepsy

The course will cover the clinical genetics, i.e. the epileptic phenotypes that are associated with specific mutations, the genetic defects of the different syndromes, and the pathophysiological mechanisms by which these defects can lead to epileptic seizures. These courses give the participants the opportunity to study all three aspects all the way from basic science to clinical practice.

Course Directors: Prof Dr Holger Lerche, Prof Carlo Marini

Duration: 6 learning units of 2 weeks each and final test

Course fee: 700 Euro each course. Self payment for approved bursaries will be 175 Euro

V. Neuroimaging

The course will cover the methodological basics of neuroimaging techniques and their application to the diagnostic work up and management of people with new onset or chronic epilepsy, adults and children.

Course Directors: Prof Dr C Chiron, Prof Dr W Gaillard

Duration: I. Mandatory Part - 4 learning units of 3 weeks each and 1 week for final task

II. Optional Part (only available if taking 1st Part) – 3 learning units of 3 weeks each and 1 week for final test

Course fee: I. Mandatory Part – 500 Euro. Self payment for approved bursaries will be 125 Euro

II. Optional Part – 300 Euro. Self payment for approved bursaries will be 75 Euro

VI. Psychiatric Aspects of Epilepsy

This course will provide neurologists an understanding of the importance of identifying and facilitating treatment of the four most frequent psychiatric comorbidities in epilepsy (depressive, anxiety, attention deficit hyperactivity and psychotic disorders) and the practical tools to achieve these goals.

Course Directors: Prof Andres M. Kanner, Prof W Curt LaFrance Jr

Duration: I. Mandatory Part – 4 learning units of 3 weeks each and 1 week for final task

II. Optional Part (only available if taking 1st part) – 3 learning units of 3 weeks each and 1 week for final task

Course fee: I. Mandatory Part – 500 Euro. Self payment for approved bursaries will be 125 Euro

II. Optional Part – 300 Euro. Self payment for approved bursaries will be 75 Euro
I\AE is pleased to announce the launch of its newly redesigned website, at the same address as the old one (www.ilae.org). We have reconceived the website to be more logical and easier to navigate. We hope you will find the new site more effective and more visually pleasing.

New features include:
- Improved Search function
- A dynamic News About Epilepsy section to keep you constantly informed about epilepsy news from around the world, and about news regarding important clinical and research developments.
- Congresses related to epilepsy can be found easily.
- New Epilepsy Care and Global Outreach sections
- New individual commission websites
- Increased capability for streaming videos
- An Epilepsia section that lists a selection of the most recent articles as well as the most downloaded articles in Epilepsia.

Please send suggestions and comments regarding the website to Jean Gotman, I\AE Director of Interactive Media, at jean.gotman@mcgill.ca, putting “I\AE website” in the subject line.

The Neuropsychology Task Force is working on evidence based neuropsychological outcomes in practice and their implications for improving diagnosis and clinical care. The Neurophysiology Task Force prepared to develop optimal EEG guidelines for “MRI negative” cases in conjunction with the Pediatric Surgical Task and is working on a retrospective study to define the utility of various tests in this cohort.

The Neuroradiology Task Force worked on a consensus paper on the use of advanced and functional imaging methods and is now trying to define the role of these imaging methods in pre-surgical evaluation for providing guidelines for children and adults.
Epilepsy Meetings of Interest

March 21 – 25, 2012
9th Asian and Oceanian Epilepsy Congress
Manila, Philippines
http://www.epilepsymanila2012.org/

April 21 – 28, 2012
66th American Academy of Neurology Annual Meeting
New Orleans, LA, USA
http://www.aan.com/go/an12

May 6 – 10, 2012
Eleventh Eilat Conference on New Antiepileptic Drugs (Eilat XI)
Eilat, Israel
http://www.eilat-ecds.com under forthcoming conferences

May 27 – June 1, 2012
12th International Child Neurology Congress & 11th Asian and Oceanian Congress of Child Neurology
Brisbane Convention and Exhibition Center, South Brisbane, Australia
http://www.cnc2012.com/

June 21 – 23, 2012
1st African Epilepsy Congress
Nairobi, Kenya
http://www.epilepsynairobi2012.org/

September 30 – October 4, 2012
10th European Congress on Epileptology
London, UK
http://www.epilepsy-london2012.org/

October 13 – 17, 2012
Society for Neuroscience Annual Meeting
New Orleans, LA, USA

October 31 – November 3, 2012
Child Neurology Society Annual Meeting
Huntington Beach, CA, USA
http://www.childneurologysociety.org/annual_meeting

November 14 – 17, 2012
7th Congreso Latinoamericano de Epilepsia (CLAE)
Quito, Ecuador
http://www.epilepsyaquito2012.org/

November 30 – December 4, 2012
66th American Epilepsy Society Annual Meeting and 3rd Biennial North American Regional Congress
San Diego, CA, USA
http://www.aesnet.org

ILAE, together with the IBE is delighted to announce that the 30th International Epilepsy Congress will be held in Montréal, QC, Canada in 2013 between the 23rd and 27th of June. What better time to visit Montréal than during 23 to 27 June 2013, when Montréal’s vibrant cultural metropolis will play host to the 34th Edition of the world famous Festival international de jazz de Montréal, the largest jazz festival in the world.