

## Welcome to the 29th International Epilepsy Congress

Dear Friends and Colleagues,

On behalf of the Scientific Advisory and Organizing Committee, it gives us great pleasure to welcome you to the **29th International Epilepsy Congress (IEC)** in the ancient city of Rome.

Continuing on from the 2009 celebration in Budapest marking the ILAE Centenary, the 29th IEC will honor and celebrate the 50th anniversary of the International Bureau for Epilepsy and the Jubilee Year of its foundation. To mark this historic event, the Scientific Advisory & Organizing Committee (SAOC) has constructed a program of great promise. Topics will explore and integrate the scientific and social aspects of the issues faced by physicians, caregivers, persons with epilepsy and by all others involved in the field of epilepsy. These topics include 'When do we consider epilepsy cured?', 'Impaired consciousness in epilepsy', 'Epilepsy during puberty – the wonder years', 'Older, slowing down and seizing up – epilepsy strikes again', 'Predicting the unpredictable: the adverse effects of treatments', 'Challenges in developing a new approach for classification in epilepsy' and 'Avoiding epilepsy deaths', which will be addressed in the Presidential Symposium. In addition, special activities have been organized to celebrate the Jubilee Year of IBE, such as a photo competition, a book of greetings, details of the history of IBE and other special Jubilee events.

Whilst we will ensure that the program appeals to each and every one of us for whom the understanding and management of epilepsy plays such an important role, we do hope that the congress will also represent an opportunity for you to explore this remarkable city at a time when Italy also celebrates its local history with the 150th anniversary of national unification.

We hope you will be able to accept this invitation and will join us in Rome to celebrate on this very special occasion.

With warm regards,



Solomon Moshé (USA)

Co-Chair

Scientific Advisory and Organizing Committee



Mike Glynn (Ireland)

Co-Chair

Scientific Advisory and Organizing Committee



Emilio Perucca (Italy)

Congress Director

Committee Members:

Federico Vigevano (Italy), Scientific Program Director

Janet Mifsud (Malta)

Giovanni Battista Pesce (Italy)

## Editorial



The 50th anniversary of an organization (as well as the 100th that the League celebrated in Budapest two years ago) is always an occasion to reflect on how much has been accomplished over

the many years. In the case of epilepsy much has been accomplished: the number of effective treatments has grown so that anything less than seizure freedom is not accepted as a success; the perception of epilepsy in many countries has improved so that people who have the disease are less likely to be ostracized; our understanding of the causes of epilepsy has improved so that we can find new and more effective treatment. These are a few of the reasons to be impressed with our accomplishments. However, as we celebrate our accomplishments, we must also consider what still needs to be done. The "to do" list for epilepsy is overwhelming considering all the problems that remain unresolved.

In the early years of the epilepsy movement progress came through the efforts of individuals who were interested in the scientific questions raised by epilepsy or who felt a responsibility to care for those afflicted with

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## President's Message

It gives me great pleasure to welcome you to the International Epilepsy Congress in Rome. This Congress is especially meaningful as it is also a celebration of the 50th Anniversary of our sister organization, the International Bureau for Epilepsy. The collaboration that we have had has been extraordinary and continues to serve as an example of what can be accomplished when professional and patient groups put their efforts behind a common cause. Working with Mike Glynn, the president of the IBE has been a true pleasure, and we look forward to our continued work together in what is becoming a truly exciting time to work in the field of epilepsy.

The League currently has over 100 chapters with seven more expected to join during the Rome meeting. If you are interested in starting a chapter in your country, you can find a list of benefits on page 13 and some instructions on getting started on page 4. You can see the full list of chapters and read the Secretary-General's report later in this issue. A brief update on the financial stability of the League can be found in the Treasurer's report on page 6. More detailed reports from both these officers can be found in the 2010 Annual Report on the ILAE website (<http://www.ilae-epilepsy.org/Visitors/Documetns/ILAEAnnual-Report2010Final.pdf>).

In addition to activities focused in our chapters and Regions, ILAE is an active partner in the Global Campaign Against Epilepsy with the World Health Organization. This long-standing partnership has resulted in demonstration projects in less developed countries, regional reports on epilepsy, legislative efforts and resources. Be sure to read the article by Hanneke M de Boer, Global Campaign Coordinator, on page 7.

ILAE is also very active on epilepsy issues through its nine Topic-Oriented Commissions, made up of members from around the world. We feature reports from four of these groups starting on page 9 this issue. Our Education efforts cross over several of the commissions and include regional and web based programs. More information on some of the web based programs can be found on page 10. The Commission on Epidemiology has several workgroups working on several projects



*S Moshé  
President, ILAE*

concerning the burden of epilepsy. These projects include working on standards for the conduct of epidemiological research, reviewing studies on the spectrum of comorbidities and looking at the reliability and applicability of testing epilepsy classification. The Neurobiology Commission is implementing educational programs for young neuroscientists as well as advanced training programs. They are also developing a comprehensive criteria to standardize preclinical analysis of new antiepileptic

therapies. The Pediatrics Commission is focusing on infancy and is engaging in a number of educational initiatives as well as creating guidelines.

On behalf of the ILAE, I'd like to thank Christophe Morris-Cooles for his efforts over the years to support a search for a cure and for his more recent support of the Morris-Cooles Prize designed to inspire creative research. Mr. Morris-Cooles has provided a report on his efforts and the Prize which appears later in this issue.

During this meeting we will be launching our revised website, [www.ilae-epilepsy.org](http://www.ilae-epilepsy.org), thanks to the efforts of volunteer Website Coordinator, Jean Gotman and staff. It has better organization, is easier to use and has a new look. We hope you will find it useful.

I'm proud to have the honor of serving you as President. ILAE is successful only due to the passion and energy of its many volunteers around the world and this passion is especially true for my colleagues on the Executive Committee. The successes that we have had and will have are due in no small part to the energy that they have brought to our goals, and working with them has made my own work more productive and fun. Please enjoy this meeting. I hope that you learn many new things that you can take back to your patients, and I look forward to seeing you again in 2013 in Montreal.

*Solomon L (Nico) Moshé  
President*

# An Introduction to ILAE

The ILAE is constituted as an international nonprofit organization and is registered in the United States. ILAE is the premiere 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. Its mission is to provide the highest quality of care and well-being for those afflicted with the condition and other related seizure disorders.

Over the years, ILAE has grown in complexity and size, and now seems a good time, briefly, to lay out its structure and component parts. For more details, readers can consult the ILAE Web site at [www.ilae.org](http://www.ilae.org).

## Executive Committee

The ILAE is overseen by an Executive Committee, currently of 12 persons (current members in brackets). The President (S Moshé) is elected by a ballot of national chapters for a four-year term. The Secretary-General (S Wiebe), Treasurer (E Perucca) and three Vice Presidents (T Tanaka, M Baulac, and M Medina) are also elected by a ballot of national chapters for a four-year term. The Information Officer (E Bertram) and the Editors-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 President (M Glynn), Secretary-General (C Acevedo) 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 Web site. The Constitution has sixteen articles, and the Bylaws have fourteen 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. Proposed changes to the Constitution are explained elsewhere in this publication.

## National 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 over 100 chapters in the ILAE, which is the greatest number in its history. National chapters range in size from almost 2,000 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 Oceania, 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 Diop), European Commission (Chair — M Bialer), Asian and Oceanian Commission (Chair — B Lee), North American Commission (Chair — S Kaut), Latin American Commission (Chair — M Campos), Eastern Mediterranean Commission (Chair — A Beydoun).

## ILAE 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 involve 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 Tanaka), Diagnostic Methods (Chair — F Cendes), Education (Chair — C Tan), Elections Commission (Chair — P Wolf), Epidemiology of Epilepsy (Co-Chairs — D Hesdorffer and E Beghi), Finance Committee (Chair — E Perucca), Genetics of Epilepsy (Chair — S Berkovic), Global Campaign (Co-Chairs — H Cross and S Li), ICD-11 Task Force (Chair — E Beghi), Neurobiology (Co-Chairs — A Nehlig and J Noebels), Neuropsychobiology (Co-Chairs — A Kanner and M Mula), Past President Advisory Council (Chair — G Avanzini), Pediatrics (Co-chairs — D Nordli and P Plouin), Strategic Planning Task Force (Chair — G Mathern), Therapeutic Strategies (Co-Chairs — B Steinhoff and S Schachter)

## Administrative Offices

The ILAE has two administrative offices. The Headquarters Office is in Hartford and the Chapter Services Office is in Dublin. The Hartford office oversees the administration and is led by Mr. Peter Berry. There are five staff employed in the service of ILAE at these two offices: Peter Berry (Chief Staff Officer), Gus Egan (Chapter Services Coordinator), Carla Glynn (Chapter Services Coordinator), Priscilla Shisler (Leadership Liaison), Donna Cunard (Finance Director), and Cheryl-Ann Tubby (Web Site Project Manager).

## ILAE Conferences and the Office of the IDM

ILAE holds a global scientific conference once every two years (Epilepsy International Congress). Each region holds a regional scientific conference every two years, in the years when there is no global conference, and every national chapter holds a national scientific conference every year. At the national conferences, the chapters also hold their

Annual General Meetings, and at the International Congresses, the ILAE also holds its General Assembly of all its national chapters. The regional and international conferences of the ILAE are organized by its own conference organizer (R Holmes, International Director of Meetings) and his office.

## Global Campaign

This is a joint ILAE, IBE and WHO initiative, launched in 1997. The first phase of the Global Campaign Against Epilepsy was devoted primarily to increasing public and professional awareness of epilepsy as a universal treatable brain disorder, and raising epilepsy to a new plane of acceptability in the public domain. The second 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 third phase was launched in 2005 and is focused on special projects in different parts of the world and on 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: E Beghi, E Bertram, M Cook, M Duchowny, R Guerrini, B Hermann, P Patsalos, M Sperling, C Stafstrom, T Tomson, A Vezzani, M Walker). *Epilepsia* was started in 1909, and currently is published monthly. It has an annual profit of \$900,000, a subscription base of over 6,600 (consortia, individual and institutional), and, in 2009, 2,048,221 articles were downloaded from its online hosts.

## Epigraph and the ILAE Web Site

In 1994, the ILAE launched its own newsletter *Epigraph*, to be sent individually to all members. This was

(continued on page 4)

# ILAE Chapters

Albania  
Algeria  
Argentina  
Armenia  
Australia  
Austria  
Azerbaijan  
Bangladesh  
Belgium  
Brazil  
Cameroon  
Canada  
Chile  
China  
Colombia  
Costa Rica  
Croatia  
Cuba  
Cyprus  
Czech Republic  
Denmark  
Dominican Republic  
Ecuador  
Egypt  
Emirates  
Estonia  
Finland

France  
Georgia  
Germany  
Ghana  
Greece  
Guatemala  
Guinea  
Honduras  
Hong Kong  
Hungary  
India  
Indonesia  
Iraq  
Ireland  
Israel  
Italy  
Jamaica  
Japan  
Jordan  
Kazakhstan  
Kenya  
Kyrgyzstan  
Latvia  
Lebanon  
Lithuania  
Macedonia  
Malaysia



Mali  
Malta  
Mexico  
Moldova  
Mongolia  
Morocco  
Nepal  
New Zealand  
Nicaragua  
Norway  
Pakistan  
Palestina

Panama  
Paraguay  
Peru  
Philippines  
Poland  
Portugal  
Qatar  
Romania  
Russia  
Saudi Arabia  
Senegal  
Singapore

Slovakia  
Slovenia  
South Africa  
South Korea  
Spain  
Sweden  
Switzerland  
Syria  
Taiwan  
Tanzania  
Thailand  
The Netherlands

Tunisia  
Turkey  
Uganda  
UK  
Ukraine  
Uruguay  
USA  
Uzbekistan  
Venezuela  
Vietnam  
Yugoslavia  
Zimbabwe

## An Introduction to ILAE

(continued from page 3)

initially sent out two to three times a year. Since 2006, four issues a year have been published — three online and one (the current issue) in print. The first online edition in 2006 was mailed to 10,587 persons. The newsletter is designed to facilitate communication of ILAE news from the central bodies to individual members in each country. ILAE also has a Web site [www.ilae.org](http://www.ilae.org). This has grown in size and complexity and in 2010 there were over 121,461 visits. *Epigraph* and the Web site are overseen by the ILAE Information Officer and Web Site Task Force.

## ILAE 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.

## How to Join the International League Against Epilepsy

The ILAE is a federation of over 100 national chapters and a person can join the ILAE by becoming a member of their national chapter.

Benefits of membership of a national chapter include:

- Full participation in national and international activities of ILAE.
- National chapter conferences and other benefits of individual national chapters.
- Complimentary copy of *Epigraph*.
- Heavily discounted subscription rates to *Epilepsia* and other epilepsy journals.
- Eligibility for membership of ILAE Commission/Task Forces.
- Access to the Web site features.

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 national chapter. You can find the contact addresses on the ILAE Web site [www.ilae.org](http://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; become part of the League!

# Report of the Secretary General for Epigraph

Ongoing applications for membership of new chapters are in process for 22 countries. Of these, seven new chapters (Kuwait, Cameroon, Nigeria, Bolivia, El Salvador, Kosovo, Sri Lanka) have received provisional approval by the ILAE executive committee and will be presented to the



*S Wiebe*

General Assembly for ratification during the 29th International Epilepsy Congress in Rome in August 2011. This brings the number of active chapters to 109. The League's secretariat has reviewed and modified the existing rules for creating a new chapter, and the requirements for creating chapters consisting of more than one country in one territory. The ILAE

reached an agreement with Wiley-Blackwell to make *Epilepsia* available on line, free of charge to our constituencies in resource-poor countries belonging to the Hinari program, enquiries about this program can be directed to Mr Gus Egan ([gus@epilepsycongress.org](mailto:gus@epilepsycongress.org)).

An amendment to the ILAE Constitution has been approved by the ILAE executive after extensive, iterative consultation with all Regional Commissions, and will be presented for ratification by the General Assembly in Rome in August. The amendment will

ensure that every region participates in the decision making process and in the management of the League's affairs.

For a full report of activities visit <http://www.ilae-epilepsy.org/Visitors/Documents/ILAEAnnual-Report2010Final.pdf>

*Samuel Wiebe*  
*Secretary-General*

## 2009-2013 ILAE Executive Committee



*President*  
*Solomon 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 Acevedo*



*IBE Treasurer*  
*Grace Tan*

# An Update from the Treasurer on the ILAE Finances

As stated in my previous report, the League has been working steadily to improve the efficiency of its operations. Compared with 2009, annual administrative costs were reduced by about 30% in 2010 and are projected to remain at the same reduced level for 2011. Thanks to a positive budget balance in 2010 and healthy investment returns in 2009 and 2010, the League's total assets grew by \$3,190,000 over the last two years, and they now stand close to \$15 million. This growth, associated with improved efficiency



*E Perucca*

of our operations, did not prevent us from actually increasing financial support to our core activities; specifically, the budget allocated and used by our Commissions rose from \$595,368 in 2009 to \$718,416 in 2010 (provisional figure), with \$1,249,270 earmarked for 2011.

Although the League has done well financially in the last two years, we cannot become complacent. Our Finance Committee is concerned about income from congresses decreasing in the future, which would significantly affect our overall

revenue. We are currently making provisions for this possible scenario, including targeting a higher level of reserves to generate sufficient returns from investments. This strategy, coupled with other sources of revenue, will allow us to maintain and even grow our operations in the long term. We have also recently established a Financial Advisory Subcommittee comprised of dedicated volunteers from the financial and corporate world. This group has been a great help in optimizing our investment policy to take into account diversified currencies and markets to be more in line with the global nature of our organization. In parallel with these initiatives, the League has developed an upgraded system to deal with conflicts of

interest and to ensure full transparency in all operations.

More information on the latest audited figures of the financials can be found in my summary published in the 2010 Annual Report (<http://www.ilae-epilepsy.org/Visitors/Documents/ILAEAnnual-Report2010Final.pdf>).

Looking forward to welcoming you all in Rome!

*Emilio Perucca*  
*Treasurer*

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## Thanks to ILAE's Financial Advisory Committee Volunteer's

How does ILAE properly manage its money? With the help of volunteers from business, banking and investments, ILAE's Financial Advisory Committee has provided invaluable analysis and advice on how best to run its business. Through regular telephone conference calls and face-to-face meetings these group has volunteered their time and energy to provide advice to ILAE's leadership on how to best invest and manage its monies. Many thanks to the committee for their efforts.



*Committee Members:*

*Front row – Sam Wiebe (Secretary General), Derek Sach (UK), John Heffer (USA), Emilio Perucca (ILAE Treasurer), Jean Gotman (Canada), Donna Cunard (ILAE Staff) and Peter Barry (ILAE Staff).*

*Back row – Gary W. Mathern (Chair); Fred Lado (USA), Sergio Bruno (Italy), Nico Moshe (ILAE President) and Irwin Engelman (USA).*

# The ILAE/IBE/WHO Global Campaign Against Epilepsy

## Activities

During the past year many activities took place within the framework of the Global Campaign. The following is a brief overview showing what happened and what was achieved.

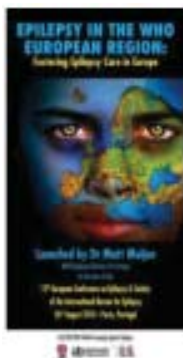
## The ILAE/IBE/WHO Global Campaign Against Epilepsy (GCAE)

In 1997 the WHO, ILAE and IBE joined forces to raise epilepsy to a level of awareness that had not been achieved ever before. This partnership is the ILAE/IBE/WHO Global Campaign Against Epilepsy with as its mission statement: *To improve the 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!

## Regional Reports on Epilepsy



To date such reports on the implementation of the GCAE, including data collected through questionnaires, have been published in all six WHO regions, the

last two being published last year.

The EMRO Regional Report on Epilepsy and the European Regional Report on Epilepsy were both launched during Regional Epilepsy Conferences in the presence of the respective WHO Regional Advisors on Mental Health Dr. Advisor Khalid Saeed and Dr. Matthijs Muijen. The reports aim at both lay and professional readers. They contain information on epilepsy epidemiology, needs and resources, thus providing an overview of the epilepsy situation in the Regions. They address the current challenges faced in epilepsy care and offer recommendations to tackle them, as well as providing a

panoramic view of the present epilepsy situation across the continent and concludes that many aspects of epilepsy care are seriously under-resourced.

## Demonstration Projects

The general objectives of the Demonstration Projects are:

- Reduce treatment gap and social and physical burden
- Educate health personnel
- Dispel stigma

The ultimate goal is: The Development of a variety of successful models of epilepsy control that can be integrated into the health care systems of the participating countries and regions and, finally, applied on a global level.

Projects are being initiated in Cameroon and Honduras. One project is being finalised in Georgia.

## Resource Assessment for Epilepsy

In collaboration with the WHO Regional Office, a draft instrument for epilepsy resource assessment in Tajikistan is being developed within the Global Campaign Against Epilepsy. The draft has undergone multiple revisions to incorporate the comments from the working group and local stakeholders from Tajikistan. This will help in detailed situation analysis, better planning and strengthening of health care for better delivery of epilepsy services.

This instrument will also be helpful to later develop a generic version that can

be used in other countries for resource and need assessment for epilepsy.

## Project on Legislation

Information was collected on existing legislation and regulations related to epilepsy in the areas of civil rights, education, employment, residential and community services, and provision of appropriate health care, from countries all over the world, in order to review the comprehensiveness and adequacy of these legal measures in promoting and protecting the civil and human rights of people with epilepsy.

A document Basic Principles for Epilepsy Legislation/Guidance instrument for developing, adopting and implementing epilepsy legislation is ready to go to print.

## Regional Involvement in GCAE Activities

Regional Stakeholders meetings were organised in 3 regions this year (AMRO, EMRO and EURO) with the participation of the WHO Regional Advisors for Mental Health of the relevant regions in order to discuss to discuss future (common) Campaign activities in the respective Regions.

During the AMRO stakeholders meeting the development of a strategic epilepsy plan for the Americas was discussed. The purpose of this plan would be that the regional leadership of PAHO which involves all Ministers of Health of all the member states will include epilepsy as a health priority for the next 10 years. This would then be the first time ever that epilepsy is considered a priority in the 100 years of PAHO's existence. The significance of entails::

- Strengthening the relationship between PAHO/AMRO and IBE/ILAE through the entire procedure, the development of the document
- This procedure and this document may be a model which can be used in the other regions of the world
- The document will lead to the commitment of all countries in the region to develop, based on the national realities, a national plan for epilepsy. All countries will be obliged to submit an annual progress report to WHO/PAHO.

This entire process was initiated under the auspices of the Global Campaign.

*Hanneke M de Boer  
Global Campaign Coordinator*



IBE/ILAE Stakeholders  
AMRO



IBE Stakeholders  
EURO



IBE/ILAE Stakeholders  
EMRO

# Topic-Oriented Commission Reports

## A Report from the Education Commission

*CT Tan, Chair, Education Commission*

### Activities by the regional academies and commissions

It is the operational roadmap that most of the education activities are organized within the Regions. This is to ensure that the activities are relevant to the area, and are cost effective. The role of the Education Commission is to coordinate the efforts by the various regional academies and commissions, and to be directly responsible for the online educational activities.

There are now regional academies in Asia (ASEPA), Europe (EUREPA), and Latin America (ALADE). The Regional Commissions in North America, and Eastern Mediterranean also have their respective education task forces. We are pleased to see the formation of the African Commission in 2010, with the appointment of Bryan Kies as the Education Officer.

The various education activities being carried out in the Regions include workshops and summer schools, visiting professorships, EEG certification, fellowships and publication of proceedings. All the Regional Congresses have attached teaching workshops. In 2010, the ASEPA organized 11 stand-alone programs and there were at least three longer duration teaching courses being held in Europe, including the San Servolo Summer School on Therapeutics. The visiting professorship project by the North American Commission continues to build close relationships between centers in North America, Latin America and the Caribbean.

The EEG certification examination was started by the ASEPA in 2005. It was a two part examination (written and oral) modeled after the American Board. By May 2010, there were 265 candidates who had taken the Part I examination with a passing rate of 63 percent, and 120 in the Part II examination with a passing rate of 65 percent. There are five Part I and four Part II examination scheduled for 2011. One of the primary goals of creating this process was to elevate the standards of EEG practice throughout the region. The comments from the candidates who have participated in the program suggest that we are achieving that goal.

Latin America and the Asian Commissions are offering fellowships for young Neurologists and Neurosurgeons to undergo training outside their countries. The ASEPA has also been publishing proceedings of the Asian Regional Epilepsy Congresses since 2004. The online version of the proceeding can be found on the ILAE website.

The Education Commission is also directly responsible for the online educational activities of the League.

### Distant learning courses

The distant learning courses by VIREPA have successfully transitioned to being a part of ILAE, with operating cost at an acceptable level. The organization of the distant education is by the Task Force on Distant Education, chaired by Walter van Emde Boas. The VIREPA will continue to concentrate on tutored interactive teaching courses; with an emphasis on learning of skills as well as knowledge.

In the 2010/2011 academic session, three courses were conducted smoothly: EEG, Clinical Therapeutics and Imaging. For 2011/2012, Pediatric EEG/Neonatology will be added as a new course.

### Other web-based education resources

As there are very few open access materials available on the internet, the Education Commission proposed to launch an open access *e-textbook on epilepsy*. Shih Hui Lim from Singapore has been appointed as the Editor. About 50-100 common topics will form the first edition with the timeline of production in December 2011.

A trial run of recapture congress workshops was carried out during the Melbourne AOEC, involving both the audio and PowerPoint slides. The materials will be uploaded to the ILAE main website after the website reorganization. For 2011, audio and PowerPoint

slide recapture is also proposed for the Rome IEC, and to progressively increase this activity in future years.

The members of *Education Commission* for 2009-2013 are: Chong Tin Tan (Chair), Tallie Z. Baram, Walter van Emde Boas, Maria Canevini, Hassan Hosny, Angelina Kakooza, Ruediger Koehling, David Labiner, Shih Hui Lim, Karupath Radhakrishnan, Marcia Elza Yacubian. The *Task Force on Distant Education* is chaired by Walter van Emde Boas, and Shih Hui Lim is the Editor of *e-Textbook*.

## A Report from the Commission on Epidemiology

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

The Commission on Epidemiology is engaged in several projects concerning the burden of epilepsy. The work that stems from this focus includes the development of standards for the conduct of epidemiological research in epilepsy in order to best study the

occurrence and burden of epilepsy; the burden of mortality in epilepsy with a specific focus upon potentially preventable causes of death; the spectrum of comorbidity in epilepsy; the development of an epidemiological definition of status epilepticus; and assessment of the reliability of epilepsy classifications.

Work on standards for the conduct of epidemiological research in epilepsy was motivated by the need to set definitions and guidelines for epidemiological studies and clinical reports requiring instruments for the definition of seizures and epilepsy and the measurement of the severity of the disease and its impact on quality of life and health care resources consumption. The document will be published as a supplement in *Epilepsia*.

The Task Force on Mortality has published a combined analysis of risk factors for SUDEP and has embarked upon a literature review based meta-analysis of potentially preventable causes of death in epilepsy, including SUDEP, suicide and epilepsy risk factors that are themselves associated with death. This work aims to provide evidence-based data on mortality with a focus on preventable risk factors.

The Task Force on Comorbidity is conducting a systematic review of studies of the full spectrum of epilepsy comorbidities, including psychiatric, neurological, cognitive and somatic. This work stems from the need to clarify if the occurrence of an association between epilepsy and other clinical conditions reflects shared etiologic factors and/or pathophysiological mechanisms or is simply a chance finding.

The Task Force on Reliability and Applicability of Testing Epilepsy Classifications aims to examine the reliability of the 1989 and 2010 classifications of epilepsy as well as the new ICD-11 classification. This is an important task to be accomplished because any classification must reflect the increasing knowledge of the disease mechanisms but, at the same time, should be a vehicle for caring physicians and scientists to speak a common language. In this regard, the reliability of old and new classification proposals must be tested before use in clinical practice and research. A user-friendly database will be developed for worldwide use with training materials and electronic clinical case reports provided in several languages.

The Task Force on an Epidemiological Definition of Status Epilepticus addresses an important issue, i.e the need to provide an operational definition of a clinical condition for which the duration is critical for the occurrence of serious and permanent complications. Thus, the definition will reflect the duration associated with sequelae rather than the duration at which drug therapy should be initiated to stop the seizure. The available human and animal literature will be examined in search of findings to identify the duration of a seizure which hallmarks poor prognosis.

*Continued on page 9*



*CT Tan*



*E Beghi*



*D Hesdorffer*



### A Report from the Commission on Neurobiology

Andres M Kanner, MD and Marco Mula, MD PhD, 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 past year, these included support of the Gordon Conference on Epilepsy held in New Hampshire, USA (August, 2010), and symposia at the European Epilepsy Congress in Rhodes (June, 2010). This year, the Commission is supporting the fourth Advanced International Course: Bridging Basic with Clinical Epileptology-4, which will be held in San Servolo, Venice, July 17-29, 2011. 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.

A second major program directed by the Commission is the advanced Workshop on Neurobiology of Epilepsy (WONOEP). This year, the 11th WONOEP will be held in Grottaferrata, Italy in August. The topic of this workshop, directed by Marco DeCurtis and Annamaria Vezzani (Milan) and the Commission chairs, is "Finding Novel Mechanisms for Epilepsy Therapy." The workshop is 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 Trial Design. Other activities supported by the Neurobiology Commission for 2011 include the organization of several parallel sessions at the ILAE Congress in Rome, and the Basic Science Workshop in Latin America in 2012.

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 National Institute of Neurological Disease and Stroke (NINDS) Director Dr. Story Landis at a recent National Institutes of Health (NIH) epilepsy workshop on antiepileptogenesis. Dr. Landis 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 trials will assemble a report entitled "ILAE Recommendations for Preclinical Epilepsy Drug Discovery: Models, Design, Best Practices and Standardization".

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.



A Nehlig



J Noebels

### A Report from the Pediatrics Commission

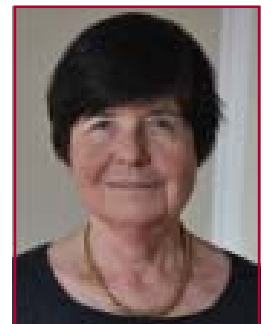
Douglas Nordli, Perrine Plouin

The Pediatrics Commission for this four year term is focusing on infancy, which is a logical continuation of the prior Commission's emphasis on neonates. As part of its mission this Commission will engage in a number of educational initiatives as well as the creation of guidelines to improve the care of all children with epilepsy. These activities include the following:

1. Developing electronic educational materials for the optimal care of children with epilepsy. This content would be specifically designed to aid colleagues in developing countries and could be elaborated in conjunction with the Commission of Education.
2. Guidelines for the evaluation of infants with epilepsy adapted for both developing and developed countries. This will be a continuation of the algorithm for diagnosis and treatment of neonatal seizures in developing countries. These guidelines would include recommendations for genetic testing, metabolic investigations, electrophysiological studies, imaging and screening for autism in infants in collaboration with the Autism Task Force. The Task Force is making steady progress and will be meeting in Rome, 2011 at the ILAE Congress.
3. Develop materials to aid in the transition of adolescents to care under adult practitioners. We will produce a document with specific recommendations to aid in the transition of care. A survey has been completed which has provided insight into the major issues. A document summarizing these issues and providing useful suggestions is the next goal.
4. Epilepsy-Autism Task Force will establish a bridge of communication between Autism Speaks (AS) and ILAE, which are two organizations with common goals, including the promotion of services and education. We are collaborating in order to coordinate educational programs on autism spectrum disorders (ASD) and epilepsy and to encourage studies on ASD and epilepsy common issues. One initiative would be to organize four translational meetings covering the following topics: classification and epidemiology, neurobiology and genetics, animal models and neuropathology, and treatment. Guidelines would emerge from these workshops and another initiative should be to implement items dedicated to epilepsy in the existing registry of autistic children.
5. The Task force for Pediatric Epilepsy Surgery will continue the work on several aspects related to epilepsy surgery practice in children worldwide. One specific goal is to prepare guidelines for surgical centers, and another is to continue the multi-institutional collaboration on outcomes. The Task Force will also be meeting at the 2011 ILAE Congress in Rome.
6. The first edition of the E-learning program on Neonatal and Pediatric EEG will start next October. The program has been developed with the Subcommittee of VIREPA. The tutors are truly international and the students are already numerous.
7. The major theme of the 2012 Summer School in San Servolo should be around the guidelines on infancy.



D Nordli



P Plouin

# ILAE – VIREPA Distance Education Programs



The ILAE-VIREPA distance learning courses are internet based e-moderated courses with downloadable learning material. To earn credits in each learning unit, tasks will be successfully completed within an active online communication process among all participants, guided by the experts. The tasks will strengthen the theoretically gained knowledge and enable transfer of this knowledge to the clinical practice of each learner.

## Clinical Pharmacology & Pharmacotherapy

### Overview

The course will cover the clinical pharmacology of currently available antiepileptic drugs (AEDs). The program will include practice oriented information aimed at the general neurologist /pediatric neurologist / pediatrician dealing with, but not exclusively involved in, epilepsy care. The online course is divided into 13 units beginning with an introduction to the VIREPA e learning platform, followed by 12 learning units of 2 weeks each.

### Entry Criteria

- 3 years of training in neurology, neuropsychiatry, clinical neurophysiology, psychiatry or neurosurgery, or combinations of these are required as entry criteria.

### Course Directors

Prof. Jacqueline French and Prof. Steve White

## EEG in the Diagnosis & Management of Epilepsy – Basic Course

### Overview

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. It is intended for neurologists, pediatric neurologists and pediatricians, dealing with patients with epilepsy, including the EEG studies of these patients. The online course is divided into 10 units, beginning with an introduction to the VIREPA e learning platform, followed by 9 learning units of two weeks each.

### Entry Criteria

- 3 years of training in neurology, neuropsychiatry, clinical neurophysiology, psychiatry or neurosurgery, or combinations of these.
- A minimum of 4 months of practical experience with clinical EEG

### Course Directors

Dr. Walter van Emde Boas and Dr. Demetrios Velis

## EEG in the Diagnosis & Management of Epilepsy in Neonates and Children

### Overview

The course will cover the basic elements of the practice of EEG in its application to the diagnostic work up and the management of neonates and children with suspected or already established epilepsy. It is intended for pediatric neurologists and pediatricians, dealing with neonates and children with epilepsy, including the EEG studies of these patients. The online course is divided into 9 units, beginning with an introduction to the VIREPA e-learning platform, followed by 8 learning units of two weeks each.

### Entry Criteria

- 3 years of training in neurology, neuropsychiatry, clinical neurophysiology, psychiatry or neurosurgery, or combinations of these.
- A minimum of 4 months of practical experience with clinical EEG
- Since this pediatric course will not deal with basic technology, it is available only for students who have successfully participated in the VIREPA EEG Basic course. Exceptions to this rule will only be made for applicants who are already competent in adult EEG and who specifically want to learn pediatric and neonatal EEG. Relevant certifications must be added to the application.

### Course Director

Dr. Perrine Plouin

## Neuroimaging

### Overview

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. Clinical cases will be presented to illustrate the role of each imaging modality for diagnosis, prognosis and management of epilepsy in adults and children, and to increase interactions between participants. The program will include practice oriented information aimed at the general neurologist /pediatric neurologist / pediatrician dealing with, but not exclusively involved in, epilepsy care. The online course is divided into 2 parts:

1st part (mandatory) beginning with an introduction to the VIREPA e learning platform includes 4 learning units of 3 weeks each. It is dedicated to MRI and one example of functional imaging technique (SPECT),

2nd part (optional and only available if taking part 1) has 3 learning units of 3 weeks each and is dedicated to the other functional imaging techniques (PET, functional MRI, multimodalities).

### Entry Criteria

- 3 years of training in neurology, neuropsychiatry, clinical neurophysiology, psychiatry or neurosurgery, or combinations of these.
- Basic practical knowledge of MRI (not only of CT)
- Daily epilepsy practice

### Course Directors

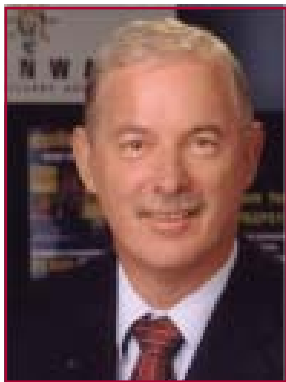
Prof. Catherine Chiron and Prof. William Gaillard

For questions, contact Priscilla Shisler ([pshisler@ilae.org](mailto:pshisler@ilae.org)) at the ILAE Headquarter Office.

# A Special Partnership

Following my election as President of the International Bureau for Epilepsy (IBE) it has been a great privilege to co-chair the Global Campaign Against Epilepsy (GCAE) “*Out of the Shadows*” with Nico Moshé, International League Against Epilepsy (ILAE) President. Since the GCAE was launched in 1997, the IBE and ILAE in conjunction with our partner, the World Health Organisation (WHO) have worked tirelessly to progress this important campaign. I would like to congratulate the GCAE on its achievements in countries and regions such as China, Brazil and Africa in reducing the treatment gap, increasing awareness and augmenting educational opportunities with significant successes in the social care aspects of epilepsy. The campaign taskforce has completed the strategic plan, which will guide the campaigns future direction in the coming years.

At the 12th European Conference on Epilepsy & Society the new Global Campaign website ([www.globalcampaignagainstepilepsy.org](http://www.globalcampaignagainstepilepsy.org)) was successfully launched and provides a comprehensive range of information, reports and articles in an easily understandable and accessible format for medical and lay representatives alike. In



Mike Glynn

addition, Dr Matt Muijen, WHO Regional Advisor for Europe formally launched the Global Campaign report *Epilepsy in the WHO European Region: Fostering Epilepsy Care in Europe*, which is available for download on the campaign website.

One of the most important recent decisions taken by the IBE and ILAE Executive Committees was the creation of a European Epilepsy Day was realised on Monday, 14th February 2011 (St Valentines Day, who has long been associated with epilepsy). Nico Moshé and I held meetings with two key Commissioners, John Dalli, Commissioner for Health and Public Policy and Máire Geoghegan-Quinn, Commissioner for Research, Innovation and Science. Our discussions focused on the need for research and awareness to improve services for people with epilepsy. To continue our European momentum, the Joint Task Force (JTF), operating as “Epilepsy Advocacy Europe”, of IBE and ILAE in Europe, hopes to submit a written Declaration on Epilepsy to the European Parliament which will support our joint efforts to improve prevention, care and quality of life for people with epilepsy. This needs the signatures of 369 members of the European Parliament (MEPs) and this is now a major work in progress.

The ILAE celebrated their Centenary in 2009 and the 29th International Epilepsy Congress (IEC) will honour and celebrate the 50th anniversary of the IBE and the Jubilee Year of its foundation. Over the past 50 years both organisations have made substantial progress in improving the lives of people with epilepsy but much work still remains. I look forward to the continuation of this collaborative work with the ILAE and on my own behalf and the members of the IBE International Executive Committee; I would like to thank the ILAE for their support and cooperation to date.

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## Editorial

(continued from page 2)

the disease. These efforts were often supported by charity from individuals and organizations. In a time when much couldn't be done, that small effort often made difficult situations a little bearable. As health care and health oriented research grew and became more centralized, epilepsy has frequently been lost in competition for support. Today, even in countries with great resources, epilepsy often remains an afterthought and is not considered a major health care priority. Many systems have no academic support for epilepsy, because it is not considered a field of great need or promise.

It is this disinterest in epilepsy that is now our greatest impediment to further progress. At this Congress we see evidence

all around us for potential therapeutic breakthroughs. However, support for epilepsy treatment and research lags well behind other neurological disorders that have less burden to society. In part this situation is our own fault: we've been too reluctant to call attention to the disease, and many people with epilepsy, because of the stigma that still lingers around the diagnosis, are unwilling to go public with their diagnosis and the problems they have experienced from having epilepsy. Epilepsy is not on the list of health care priorities for many countries, but we may be seeing a change in that situation. The WHO has issued a report on epilepsy in the European Region. The Pan American Health Organization has issued a report

on the many issues faced by patients with epilepsy and their families. The Institute of Medicine in the United States is working on a similar study. All are dealing with the many specific needs for epilepsy care. In Europe, our epilepsy organizations are working hard to have a declaration on epilepsy from the European Parliament that will encourage member nations to give epilepsy the priority that is deserved. However, as important as it may be for these organizations to support improvements in epilepsy care, these documents are only the start. These reports are our call to action. All of us involved with epilepsy have to use these reports to assure that appropriate resources are directed to improvements in

treatment, through research and health care resources.

While we celebrate our many accomplishments here in Rome, we must also resolve that at the next major anniversary we will have even greater successes in our mission to assure that no one's life is limited by epilepsy. Concerted effort by our organizations to make epilepsy important may be the best anniversary gift we can give ourselves and to people with epilepsy.

Edward H Bertram III  
Information Officer

In the case of epilepsy much has been accomplished: the number of effective treatments has grown so that anything less than seizure freedom is not accepted as a success; the perception of epilepsy in many countries has improved so that people who have the disease are less likely to be ostracized; our understanding of the causes of epilepsy has improved so that we can find new and more effective treatment.

# Amendment of ILAE Constitution and By-Laws

At the International Epilepsy Congress in Rome, the chapters will be asked to vote on proposed changes to the League's Constitution, the document that establishes the structure of the League and responsibilities of its officers. The Constitution should not be viewed as something that is fixed and permanent, rather it should reflect the changes that happen in the life of any healthy organization. Over the last several years there has been a major effort to review the current state of the League, which has become truly international in the last several decades as it has grown to have a presence across the globe. As a result of that review, there are a number of changes that are being proposed for the Constitution. To help everyone understand the changes, we are listing them below so that all may see how we continue our efforts to assure that the League's function reflects the evolution that is happening in the world of epilepsy.

## Amendment of the Constitution:

The members of the Task Force are Drs Michel Baulac, Marco T Medina, Simon Shorvon, Samuel Wiebe and Tatsuya Tanaka (Chair). The ILAE has achieved world-wide success over the first century of its existence. This success is reflected by the growth of regional activities and collaboration among different regions (Asia/Oceania, Europe, North America, Latin America, Eastern Mediterranean and Africa). To represent the League's constituency better, the Task Force is proposing a series of changes to the League's constitution to ensure participation of all regions in the governance of the League at the highest level with membership to the Executive Committee and the Management Committee. Through the previous term (2005-2009), Drs Emilio Perucca, Nico Moshe and other members of the Executive Committee had been finalizing the proposal for the ILAE Constitution. The present Task Force took over this effort and frequent meetings were held during past two years.



Tatsuya Tanaka

The proposed of Constitutional Amendment by the Constitution Task Force was approved by the Executive Committee Meeting on March 26, 2010 in Ghent with the goal to have the Amendments presented at the

2011 Rome International Epilepsy Congress for approval by the chapters at the General Assembly. The new structure would then be implemented for the 2013 Executive Committee Election. The proposed changes are highlighted below and listed by Constitution article.

### Article VI.

- Chapter Constitutions must be kept in the League office.
- Changes to Chapter Constitution and Bylaws should be submitted to the Executive Committee and General Assembly.
- In the creation of new chapters in the future the League will accept applications from two or more states to allow chapter formation in groups when a single state cannot support a chapter
- A list of names and addresses of members must be submitted to the Secretary-General at the time of new Chapter application

### Article VIII.

- Composition of the Executive Committee:
  - **Voting members:** President, Vice-President, immediate Past President, Secretary General, Treasurer and the Chair of each of the ILAE recognized regions. There will no longer be three vice-presidents, and the Information Officer is no longer a constitutional member of the Executive Committee.
  - **Ex-officio non-voting members:** President, Secretary-General and Treasurer of the International Bureau for Epilepsy, and Editor(s)-in-chief of *Epilepsia*.
- No person may occupy a seat on the Executive Committee for a period

exceeding a maximum of sixteen years.

- Composition of the Management Committee: The President, Vice President, Secretary-General, Treasurer and Immediate Past President.
- The Elections Commission will include one person from each of the ILAE recognized regions
- Elections Commission is to conduct the elections and establish appropriate procedures as described in the bylaws and that are not in conflict with the Constitution.
- Election procedures have been moved to the By-laws

### Article IX.

- Wording of section 7, dealing with timing and organization of International Congresses was impractical and unenforceable. The time and place of future Congresses are a joint decision by ILAE and IBE, and planning has to occur at least two years in advance. Therefore Section 7 deleted.

### Article XI.

- The maximum duration of office of the Editor(s) of *Epilepsia* is now defined as eight years.

### Article XIII.

- Requires that the rules of procedures of Regional Commission are consistent with the Constitution and Bylaws of the ILAE, that these are kept in the central ILAE office, and that any changes be ratified by the ILAE Executive Committee.

## Amendment of ILAE Bylaws

In the ILAE Constitution Article VIII – 9, there is following wording:

“The Executive Committee shall have the power to formulate at any time By-Laws not in conflict with the Constitution. These By-Laws are legally binding, but a posteriori corrective action may be taken by the General Assembly to revoke or amend these rules.”

Consequently, once the Amendment of Constitution is approved by the General Assembly, the Constitution Task Force and Executive Committee members will start to amend the By-Laws to assure that they are aligned with the approved constitution.

## Summary

We believe that the amended Constitution will allow the ever changing ILAE to reflect the truly international constituency that has developed in the last 20 years and to be a better supporter of the diverse needs of our many members. We urge all chapters to consider these changes and to support the ratification of this important document at the General Assembly in Rome.

Tatsuya Tanaka

First Vice-President, ILAE

Chair of the Constitution Task Force

# The Morris-Coole Epilepsia Prize

Many years ago a fifteen-year old boy whose world revolved around rugby and swimming was diagnosed as having epilepsy. He was told it was idiopathic. His question was not "Why me?" but "What causes it?" But answer came. There was the paradox of a phenomenon which was as old as the human race, but about which so little was known. As with much else, it is the fear of the unknown which is at least as great as that which is known.

So in this way he was gifted the inspiration to discover, and who better to experiment on but oneself? Successes were rare and failures common, but some of the more resolute theories hold fast to this day. In time, after he became a trustee of what is now the Epilepsy Society at Chalfont, England with its close links to the National Hospital, London he recalled the Chinese proverb:

*"To the frog in the well the sky is no bigger than a bucket"*

From there on, he looked out to the sky and the cosmic brain beyond. Today, he stands in relatively the same position as did his consultant fifty years ago but what he is looking at was unimaginable then.

The Morris-Coole Trust was formed in 2007 following the death of his parents. Through discussions with epileptologists at Chalfont, the Institute of Neurology and the National Hospital the Morris-Coole Prize was inaugurated. The formal mission of the Trust is to encourage, support and stimulate scientific and clinical research into the understanding, causes and control of epilepsy. The support of the ILAE and *Epilepsia* has been invaluable in realizing the ideals of Prize. Without that common purpose the Prize would never have become what it has.

Since 2007 the Prize has been awarded annually to the principal author of the paper adjudged to have been the best to have been published in *Epilepsia* during the preceding calendar year. There is no age limit on the eligibility of authors, but the aim has been to attract the best young researchers and serve as an incentive to them to achieve excellence in this field. This has the complementary effect of creating role models in time.

The quality of the papers has exceeded all expectations. The first winner was Zita Gajda (Szeged), researching gap junction channels and AEDs, followed by Nicola Marchi (Cleveland) on blood brain barrier, Julia Jacobs (Montreal) on an

indicator of seizure onset areas, Yao-Chung Chuang (Taiwan) on the interaction between AEDs and atherosclerosis and, most recently, Laura Jansen (Seattle) on receptor expression in pediatric epilepsy. The spectrum of the research alone is impressive. The content is even more so.

In 2011 the Prize has undergone change. The Trust and the ILAE have combined to ensure the continuing future of this Prize which is widely regarded as being one of the most prestigious accolades for research into epilepsy. It will be called the Morris-Coole Epilepsia Prize. What has previously been solely a money prize will now be a money prize of US\$5,000 but will have additionally a Prize Insignia. The Trust appreciates that the award of the Prize should carry with it a personal token to mark the individual achievement. Rather than a certificate, it will be the insignia. All previous winners will receive the insignia.

The insignia will be unique. It has been commissioned by the Trust from the artist/designer Ginnie de Vroomen, and will be made by the renowned master goldsmith Leo de Vroomen in London. The insignia will be made in gold and silver in the form of the initials of the Trust, and embodies characteristic features of spike and wave. It is a rare and fine piece of jewellery in its own right and may be worn as a brooch, or as a distinctive lapel pin. How it is worn will be determined by individual taste and flair.



Leo de Vroomen is himself a prize-winner of great distinction,

having twice been awarded the De Beers Diamonds International Award and, in 2001 the "Oscar" of the jewellery world, the Award for Best Design, Haute Couture. It is with great pleasure that we thank

him for expressing his skills to complement the Prize.

In all other respects the Prize will continue to be judged and awarded as before, and the winner will be invited to present the designated Morris-Coole Epilepsia Lecture at the annual International Congress.

As to the future, when we reach out into the cosmos who knows what we will find.

*Christopher Morris-Coole  
Bloomsday 2011*

## Benefits of Joining ILAE

- The ILAE's **mission** is to ensure that the health professionals, patients and their care providers, governments, and the public world-wide 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 join a network of over 15,000 epilepsy professionals from over 100 different countries, organized into 6 different worldwide regions (Africa, Asia-Oceania, Europe, Eastern Mediterranean, Latin America and North America)
  - Chapters have access to resources allocated to Regional Commissions for 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 education and treatment in their country.
  - Through the ILAE member-driven regional conventions, 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.



# New ILAE Website

Text for Epigraph and for an email blast to be sent when new site is launched

ILAE is pleased to announce the launch of its new web site, at the same address as the old one ([www.ilae.org](http://www.ilae.org)). We hope you will find the new site more effective and more pleasing. We have re-organized it to be more logical, and you should be able to find your way more easily. The "search" function has also been improved. The site includes a "News" section that will keep you constantly informed about epilepsy news from around the world, and about news regarding important clinical and research developments. All information about Congresses related to epilepsy can be found easily. We have new sections such as "Epilepsy Care" and "Global Outreach". The "Epilepsia" section lists a selection of the most recent articles as well as the most downloaded articles in Epilepsia.

Please send suggestions and comments regarding the web site to Jean Gotman, ILAE Director of Interactive Media, at [jean.gotman@mcgill.ca](mailto:jean.gotman@mcgill.ca), putting "ILAE web site" in the subject line.



# Epilepsy Meetings of Interest

## **4th Eilat International Educational Course: Pharmacological Treatment of Epilepsy**

Princess Hotel, Eilat, Israel  
18 - 25 September, 2011  
<http://www.eilat-aeds.com> under Forthcoming  
Conferences

## **4th CAAE International Epilepsy Forum (CIEF) Formerly the Beijing International Epilepsy Forum**

Nanjing City, Jiangsu Province, People's Republic of China  
21 - 24 September, 2011  
<http://www.caae.org.cn>

## **5th World Congress on Controversies in Neurology: Life Course Related Conditions (CONy) – Asia Pacific**

Beijing, China  
13 - 16 October 2011  
[http://www.comtecmed.com/cony/2011/  
Default.aspx](http://www.comtecmed.com/cony/2011/Default.aspx)

## **5th Asian Epilepsy Surgery Congress**

Annual Scientific Meeting of the Hong Kong Neurosurgical  
Society  
Hong Kong Academy of Medicine, Aberdeen, Hong Kong  
9-12 November 2011  
Registration deadline: 30 September 2011  
<http://www.aesc.hk/>

## **Neuroscience 2011 - Society for Neuroscience Annual Meeting**

Washington, DC  
12-16 November 2011  
<http://www.sfn.org/AM2011>

## **XXth World Congress of Neurology**

Marrakesh, Morocco  
12-17 November 2011

## **American Epilepsy Society 65th Annual Meeting**

Baltimore, MD, USA  
2 – 6 December, 2011

## **15th Annual Meeting of the International Symposium on Surgery for Catastrophic Epilepsy in Infants**

Tokyo, Japan  
Abstract Submission Deadline: 31 October 2011  
18 - 19 February, 2012  
<http://www.iss-jpn.info>

## **Eleventh Eilat Conference on New Antiepileptic Drugs (Eilat XI)**

Eilat, Israel  
6 - 10 May, 2012  
<http://www.eilat-aeds.com> under Forthcoming  
Conferences

## **12th International Child Neurology Congress & 11th Asian and Oceanian Congress of Child Neurology**

Brisbane Convention and Exhibition Center, South  
Brisbane, Australia  
27 May - 2 June, 2012  
<http://www.icnc2012.com/>

## **9th Asian and Oceanian Epilepsy Congress**

Manila, Philippines  
21 - 25 March, 2012  
[www.epilepsymanila2012.org](http://www.epilepsymanila2012.org) (available February 2011)

## **10th European Congress on Epileptology**

London, UK  
30 September - 4 October, 2012  
<http://www.epilepsy london2012.org>

## **7th Congreso Latinoamericano de Epilepsia (LACE), Quito 2012**

Quito, Ecuador  
14 - 17 November, 2012  
<http://epilepsycongress.org/index.php?id=71>

ILAE, together with the IBE is delighted to announce that the 30th International Epilepsy Congress will be held in Montreal, QC, Canada in 2013 between the 23rd and 27th of June.



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All communications should be directed to Cheryl-Ann Tubby at [epigraph@ilae.org](mailto:epigraph@ilae.org),  
or by telephone 860.586.7547, or fax 860.586.7550

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