# INTERNATIONAL LEAGUE AGAINST **FPII FPSY**

# Editorial



Professional meetings and congresses are designed to pass the latest scientific and clinical developments on to colleagues in the field and to stimulate new ideas. In this way, the congresses meet a

key goal of most societies to educate and to foster progress. These meetings serve another, often less appreciated, purpose, which is to provide a venue in which members of the society can come together and informally discuss their own findings or clinical problems and learn from others on a one on one basis. Ideally, collaborations between institutions or across national boundaries will develop. These informal meetings are often the most important for moving a field forward, and the congresses help by providing a place where people with common interests could meet and talk, at times by pure chance. In this, the year of the Regional Epilepsy Congresses, we encourage all of our members to make use of this outstanding opportunity to learn the latest in the plenary sessions and symposia. More importantly we hope that you spend time with colleagues from around the globe to learn about common problems and to develop solutions that will work in a particular environment.

(continued on page 6)

# IN THIS ISSUE

President's Message	1
Editorial	1
An Introduction to ILAE	2
ILAE Chapters	3
How to Join the ILAE	
Global Campaign Report	4
2009-2013 Executive Committee	
Treasurer's Report	
Topic-Oriented Commission Reports	
ILAE Epilepsy Academy	
A Special Partnership	
The ILAE Web Site	
Upcoming 2010 Congresses	

# President's Message

assumed the Presidency of the League six months ago. Much has been accomplished through your dedication and the coordinating efforts of the Executive Committee that is directing the League's activities in an open and transparent fashion. I'd like to take this opportunity to thank all of you who have worked so hard to promote and push forward our League's agenda.

To start, the Commissions have been formed and are developing their

respective plans in alignment with the new Strategic Plan, which is posted on the Web. One aspect of this plan is the development of broad collaboration across the Commissions as they work together to succeed in areas where their goals overlap. To stimulate this collaboration the Commission Chairs have met twice and have had an opportunity to exchange ideas and to develop these active collaborations. Coordinating these Commission efforts will require new methods of communication that allow the individual working groups to stay in regular contact through Web conferencing and Web file rooms for each Commission and its liaisons. Ed Bertram is leading this effort. Gary Mathern and the Strategic Task Force will continue to monitor our progress toward achieving our strategic goals as a team.

Sam Wiebe, our Secretary-General, working with Peter Berry, our Chief Staff Officer, has reorganized the office to improve its efficiency. Sam is also supervising the changes in our office and personnel dealing with chapter issues, including the maintenance of effective databases, chapter development and growth. Effective 1 January 2010, these functions that were previous handled by the Brussels office will now be served by Chancel in Dublin. Chancel is focused on epilepsy and has been managing our Congresses for a number of years, as we and IBE are its only clients.

The Strategic Plan recommended (section 3.3.1) the establishment of the Finance Committee, to be chaired by the Treasurer, Emilio Perucca. It also recommended (section 3.3.2) that we establish a Financial Advisory Council including professionals from the corporate environment. This council would offer advice to ILAE regarding its investments and reserve policy as well as



S Moshé President, ILAE

potential fund-raising opportunities. Members of this Council will have expertise in finance, be willing to volunteer their time and ideally have an interest in epilepsy. The first meeting of the Finance Committee was held in Boston, on 6 December 2009.

THE ILAE NEWSLETTER • ISSUE 2 • 2010

The Global Campaign Secretariat met with the WHO leadership in October 2009. To promote and facilitate initiatives for improving the standards of comprehensive epilepsy care, including diagnosis, treatment,

and social care in sustainable ways, the Secretariat created a Task Force headed by Shichuo Li and Helen Cross to develop the plan of action for the next several years. The Task Force will submit their recommendation by the Spring of 2010.

The Executive Committee negotiated a new contract for *Epilepsia* with Wiley-Blackwell, the current publisher. This contract was signed in December 2009 and ensures the continuing growth of our publication agenda. Together with the IBE, we have reached agreement with Chancel to continue organizing our outstanding Congresses.

The Executive Committee is also actively working on several important issues:

- 1. The development of a transparent conflict of interest policy regarding our interactions among ourselves as well as our various partners. Michel Baulac and the Past President, Peter Wolf, are heading this project.
- 2. The 1st Vice President, Tatsuya Tanaka together with Michel Baulac, Marco Tulio Medina and Simon Shorvon are working on putting the final touches on the Constitutional Amendment to be voted on at the Rome Epilepsy Congress in 2011. Our goal is to ensure global representation in the Executive Committee.

ILAE has been hard at work building strong relationships with health organizations and with corporate partners. Because the League is a federation of Chapters, our strength derives from our collective experience, vision, and concept of how we can all work together to improve education and reduce the treatment gaps in every part of the world. Several opportunities

Continued on page 5

# An Introduction to ILAE

he 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.

# **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 (E Hargis) 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: European Commission (Chair – M Bialer), Asian and Oceanian Commission (Chair – B Lee), North American Commission (Chair – J French), 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 – CTan), 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 — M Glynn and S Moshé), 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), Emily Fournier (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 encourgae agvernments 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 2008, 869,249 articles were downloaded from its online hosts.

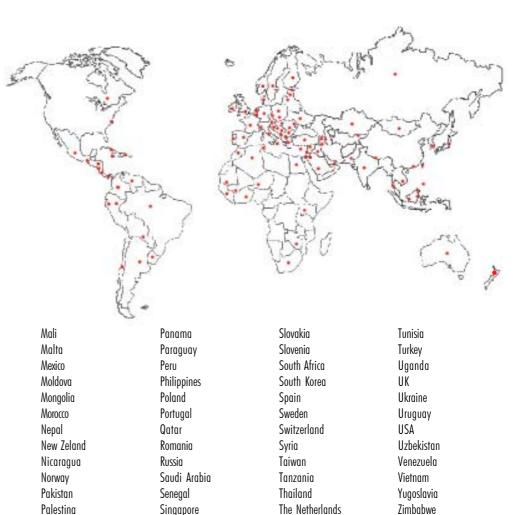
# Epigraph and the ILAE Web Site

In 1994, the ILAE launched its own newsletter *Epigraph*, to be sent individually to all members. This was (continued on page 3)

# **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



#### An Introduction to ILAE

#### (continued from page 2)

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. This has grown in size and complexity and in 2009 there were over 704,653 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.

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!

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

# The History

Since its inception in 1997, the GCAE strategies and activities have been designed according to the Global Campaign mission statement: "To improve the acceptability, treatment, services and prevention of epilepsy worldwide." Both ILAE and IBE are in official relations with WHO and over the years have contributed to a number of departmental activities in the area of neurology such as the production of the report "Neurological Disorders: Public Health Challenges" (2006).

# Global Campaign Activities to Date Include:

- Regional Conferences were organized in all six WHO Regions between 2001 and 2004. As a result of these Conferences, Regional Declarations on Epilepsy have been developed in all Rrgions.
- Regional Reports on Epilepsy have been published in: AFRO, AMRO (Spanish version), SEARO and WPRO. The reports for the European and EMRO Regions will be published this year (2010). The reports provide basic knowledge on epilepsy and facts about the epidemiological burden in the region, as well as proposing the next steps to be taken.
- Demonstration Projects have been developed, implemented and completed in: China, Brazil, Zimbabwe and Senegal. A project is ongoing in Georgia.
- Within the WHO Atlas Project an "Atlas: Epilepsy Care in the World" was developed and published in 2005.
- A grant for a pilot project on stigma in epilepsy was obtained from the Fogarty Foundation (NIH, USA) in collaboration with the University of Liverpool (UK). This project led to four publications in: the *Lancet* and *Epilepsy and Behavior*.
- Information on the epidemiology of epilepsy worldwide has been collected to calculate the burden of epilepsy.
- Guidelines for the treatment of epilepsy in childhood and adolescence are being drawn up in collaboration

with the WHO Department of Child and Adolescent Health and Development. Evidence-based guidelines for the management of neonatal seizures in resource-poor settings have been completed.

- A project on "epilepsy and legislation" led to the development of two documents: "Guidance instrument for developing, adopting and implementing epilepsy legislation" and "Basic principles for Epilepsy Legislation," which should be published shortly.
- A survey to evaluate the results of Campaign activities on a national level was performed in 2009. The following are some of the outcomes:
  - Since 1997, 135 IBE/ILAE organizations in 103 different countries organized hundreds of Global Campaign-related activities, covering 5.5 billion of the world population (86%).
  - Two-thirds of Campaign activities were reported to be either very successful or moderately successful. Thirty-nine percent of respondents reported that their activities were very successful.
  - Ninety percent of those surveyed said they would continue to be active in the Global Campaign in the future.

### **The Present**

The past four years have been rather quiet as far as Campaign activities are concerned. Although existing activities moved forward, hardly any new ones were initiated. The newly-elected Presidents of ILAE and IBE, Nico Moshé and Mike Glynn, decided that because the success of the Global Campaign is of paramount importance to both IBE and ILAE, they will lead the effort together, with Tarun Dua (representing WHO), thus forming the Campaign Secretariat. Hanneke de Boer will continue to be involved in the Campaign as its Coordinator.

The activities started with a meeting of both Presidents with the WHO leadership in Geneva in October 2009, during which the future direction of the Global Campaign and potential future activities were discussed. It was agreed that for the Campaign to maintain its current success and aim for an expansion in activities, "more hands on deck" would be imperative.

Following this, the Presidents decided to set up a Global Campaign Task Force to help achieve this goal. The Task Force members are representatives of their respective regions, and, most important, are people who are willing to "work." Helen Cross from the UK and Shichuo Li from China have been invited to act as Co-Chairs of the Task Force. Members include (in alphabetical order): Carlos Acevedo, Chile; Raida Al Baradie, Saudi Arabia; Charles Begley, USA; Steve Schachter, USA and Anthony Zimba, Zambia. Both Presidents, Tarun Dua (WHO), Emilio Perucca (Treasurer, ILAE) and Sam Wiebe (Secretary-General, ILAE) will serve as Ex-Officio members, while Hanneke de Boer, as the Coordinator of the Campaign, will participate in all meetings. Each member of the Task Force was asked to appoint a young person from their respective country to assist them with the work involved. Thus, the Task Force would also create a

mechanism for capacity building. One of the first charges of the Task Force is the development of a strategic plan for the Campaign which should be completed by March 2010.

In the meantime the following activities are already taking place:

- Investigations into the feasibility of new Demonstration Projects in Cameroon, Ghana, and India.
- A final report on the "Demonstration Project: Epilepsy Management at Primary Health Level in rural China" was completed, published and launched.
- Preparations for the publication and launch of the Eastern Mediterranean and European Regional Reports on Epilepsy.
- Finalization of the publication on Legislation and Epilepsy
- Finalization of the document: "12 Years of Global Campaign."

Hanneke M de Boer Campaign Coordinator



#### GCAE Task Force

Front: Left to right: Mike Glynn, Tarun Dua, Helen Cross, Hanneke M de Boer, Shichuo Li

Back: Left to right: Anthony Zimba, Charles Begley, Emilio Perucca, Raidah Al-Baradie, Nico Moshé, Sam Wiebe, Carlos Acevedo

(Steve Schachter not present).

# 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



Information Officer Edward Bertram



3rd Vice President Marco T. Medina



IBE President Mike Glynn



Epilepsia Editor-in-Chief Phil Schwartzkroin



IBE Secretary- General Eric Hargis



Epilepsia Editor-in-Chief Simon Shorvon



IBE Treasurer Grace Tan

#### President's Message

(continued from page 1)

and challenges were identified, and the League is actively pursuing the options. For example, we have formed a partnership with Autism Speaks to develop a better understanding of the cognitive comorbidities that plague some people with epilepsy.

To move forward with our mission we will need your feedback to:

1. Develop the message that will ensure that Epilepsy receives the attention it deserves among governments and the various policy-makers as well as funding agencies to secure that resources will be available to reduce the knowledge and treatment gaps through effective translational research. Working with IBE, WHO, as well as our other partners worldwide, we hope to craft a message that emphasizes the importance of epilepsy as a chronic disorder that hurts so many lives, not just the lives of the people with the disorder. However, we also want to give the hope that something can be done and we can

provide sustainable access to care if we have the support for developing new and better treatments.

- To identify the 'BIG IDEA' Gary Mathern, the Chair of the Strategic Task Force is in the process of communicating with the Chapter leaders asking:
  - What if we had the opportunity to take on a significant major initiative that would impact epilepsy research, education, and patient care for years to come? What project/program would we want to accomplish?
  - What if we had access to additional resources — people and money — for a program of monumental proportions, not only to set the program into motion but also to guide its progress and effectiveness for years to come? What kind of program would we want to see ILAE and our partners establish?

We need you to become engaged in this process. We want you to recommend one or two ILAE initiatives that would have the most impact on you and your region of the world — and tell us why the impact would be significant. Over the next several months, we need you to give this process your serious attention and strong endorsement. We want your ideas, your expectations, and your recommendations. Send them to Bigldea2010@ilae.org.

This is the year of the Regional Congresses. These Congresses are vital for the dissemination of information within and across regions. They also form a platform to launch major initiatives such as Regional Declarations and establish effective collaborations to improve the care of people with epilepsy. The members of the Executive Committee who will be attending these prestigious events will have a great opportunity to have face to face meetings with the Regional Commissions and the local Chapters at the Chapter Conventions to address your concerns, obtain feedback on our progress as an organization and, most importantly, to exchange ideas and to hear from all of you regarding our action items and other issues that are important for your Chapter and Region. Open dialogues are crucial to ensure the vitality of our League.

In my short time as President, I have been impressed by the dedication, innovation and enthusiasm that so many are bringing to the cause of epilepsy. I thank all of you for the long hours that you have devoted to working for our League's mission and I am looking forward to seeing you at your Regional Congress.

Solomon L (Nico) Moshé President

# Treasurer's Report

When I took up my position of ILAE Treasurer in June 2009, the world was in the middle of the worst financial crisis since the beginning of the last century. Many professional and scientific societies have been affected by the global downturn, but

thanks to a conservative investment policy, ILAE has been able to minimize potential losses. In fact, some losses have already been recovered thanks to the rebound of financial markets in late 2009. These recent developments justify cautious optimism about our financial outlook.

A new contract has been signed with Chancel, the company that works exclusively for ILAE and IBE in organizing international and regional congresses. We look forward to a continued collaboration with the goal of further improving the quality of our congresses not only in terms of scientific quality but also in terms of financial viability. As of January 2010, Chancel's office in Dublin will be providing support to our Chapters, a task previously done in the now closed Brussels office. This move will improve communication, eliminate some duplication of work, and produce significant cost savings to ILAE. A new contract has also been signed with Wiley-Blackwell for the publication of Epilepsia. Thanks to the good work of our editors, Philip Schwartzkroin and Simon



#### E Perucca

the journal. The new contract signed with the publisher will bring to the ILAE a minimum annual revenue of US\$1.2 million over five years, providing the League with some financial stability well into the next term of office.

Shorvon, the focused

efforts of our publisher

and increasing support

from our readership, the

quality of our journal

has increased steadily.

This is good news not

only for ILAE's prestige

and for epileptology as

a discipline, but also for

the "market value" of

With this knowledge, I can confidently describe the ILAE finances as healthy. At the end of 2009, our investment portfolio totaled US\$9,486,000 most of which is invested in long-term funds, which provide reasonable financial security for the future. Expected income from the journal royalties, from congress surpluses and from investments should allow us to not only sustain but also expand our activities to fulfill our mission. A dedicated Task Force, chaired by Vice President Michel Baulac, is currently working with the Executive Committee and with the Chairs of our Commissions in reviewing projects proposed by Regional and Topic-Oriented Commissions. Overall, we anticipate that in fiscal year 2010 we will be able to allocate over \$1 million to activities generated by our Commissions, thereby

providing an important boost to the implementation of the Strategic Plan.

As explained by our President in the previous issue of *Epigraph*, the Strategic Plan recommended establishing a Finance Committee, chaired by the Treasurer. This group is responsible for monitoring all ILAE financial matters and making timely recommendations to the Executive Committee on:

- (i) ways to secure and diversify our main sources of income;
- (ii) ensuring that income and expenses are in line with our goals and aims;
- (iii) ensuring high professional standards in terms of financial management and internal control systems;
- (iv) reducing the organization's fixed costs, including streamlining our various administrative offices; and
- (v) monitoring ILAE's financial business plan, reserve policy, and investment portfolio.

The newly created Committee met for the first time in Boston in December 2009. Members of the Committee include Ahmad Beydoun, Martin Brodie, Manuel Campos, John Heffer, Gary Mathern, Mike Glynn, Nico Moshé and Chong Tin Tan, in addition to our Chief Staff Officer, Peter Berry, our Financial Manager, Donna Cunard, and myself. One of the tasks on which we are currently focusing is a review of ILAE's investment policy, as well as an exploration of opportunities for diversifying our sources of income. In that regard, the Strategic Plan also recommended that we establish an external Finance Advisory Council and a Resource Development Task Force, including senior professionals from the corporate environment. The goal is to assemble a group of committed, high-level professionals with different backgrounds and relevant expertise, who can advise the Executive Committee and the Finance Committees on financial policies and fundraising opportunities. This will require working with a variety of external partners and it is essential that the interactions have the highest level of transparency and clear rules to address potential conflicts of interest. In this respect, we are grateful to Michel Baulac and to Peter Wolf, who are finalizing an excellent document outlining the procedures to ensure the highest ethical standards in our organization.

The initiatives and goals which I have described require a lot of collaborative work, and I am fortunate to be part of a great team, which includes not only all Executive Committee members but also the Chairs and members of the many Commissions with whom I frequently interact. Last, but not least, I wish to thank our efficient Financial Manager, Donna Cunard, for all her support.

Emilio Perucca Treasurer

#### Editorial

#### (continued from page 1)

In the past and still today, behind the many public events at these congresses, the international and regional leadership met to plan the direction of the League and its regions. Historically, these meetings were restricted to a few senior members who would set priorities for the League based on information from a few regions. Although the global agenda was always considered, decisions often took on a more regional perspective. In the last years, however, this pattern has started to change. Key to this change has been a globalization of the leadership. This globalization ensures that every region has a seat at the table. Another change

has been an opening up of the decision process to a much broader representation of the membership. The Strategic Plan, which is the auide for the Legaue over the next years, was developed using people from many backgrounds who came together with the common purpose of setting direction and priorities. These goals appear in this edition of Epigraph with the leadership and some of the Commissions presenting the broad and ambitious program. We hope that you will use these outlines for future development to guide your own discussions with colleagues as you consider potential collaborations.

However there is something more exciting, as mentioned recently by Gary Mathern, Chair of the Strategic Planning process, and Nico Moshé, the League's President: we are looking for ideas on a grand scale, the so-called "BIG IDEA." As described in Nico's article, this"BIG IDEA" is a project that the League could take on a global scale with the collaboration of our partners toward the goal of improving the lives of people with epilepsy. We are asking that as you meet with your colleagues at this year's congresses you talk about what we might, as a society, take on. And we want to hear your ideas. At the congresses, stop the leadership and

share your ideas. Alternatively, you can e-mail them to us at

Bigldea2010@ilae.org. Because the needs and perspectives vary considerably across regions and countries we need to hear from all of you in the process of how we may, as the epilepsy community, move the treatment of all aspects of epilepsy forward.

Edward H Bertram III Information Officer

# Topic-Oriented Commission Reports

### A Report from the Classification and Terminology Commission

Ingrid E Scheffer, MD (Commission Chair) and Anne T Berg, PhD (Task Force Chair)

With its recent work, the Commission on Classification and Terminology has brought the Organization of the Epilepsies into the 21st century. Significant progress in thinking has occurred in terms of concepts, terminology and approaches to organization of the epilepsies. We thank the epilepsy community for their valuable insights and comments during the recent online



A Berg and I Scheffer

review of the new organization which culminated in the Executive Committee of the ILAE accepting the Commission's report and its recommendations.

The critical changes relate to the definitions of generalized and focal seizures, simplification of the classification of generalized seizures, and recognition that focal seizures should be characterized according to their manifestations as no natural classification exists. From the point of view of epilepsies, the concepts of generalized and focal have been removed so as to separate the clinical manifestations from the underlying pathophysiology. The terms idiopathic, symptomatic and cryptogenic are replaced by genetic, structural-metabolic and unknown. Modified concepts accompany these new terms. The term "syndrome" is reserved for electro-clinical syndromes and is not applied to just any form of epilepsy.

Unlike the previous classification of the epilepsies, the organization of the epilepsies should be flexible. One option is to consider the epilepsies in order of diagnostic specificity first, then for epilepsies that do not fit clear electro-clinical patterns, by what is known of the underlying cause. Thus, epilepsies might be organized first as a) electro-clinical syndromes, b) non-syndromic epilepsies with structural-metabolic causes and c) epilepsies of unknown cause. Within these categories further organization might occur according to age of onset or specific underlying cause. A key feature is that organization within as well as across these divisions is flexible and multidimensional so that epilepsies can be organized in the best way possible (e.g., age of onset, or by seizure type, and so forth) for a specific purpose.

In its 2009-2012 term, the new Classification and Terminology Commission will develop educational materials regarding the new organization which will be made available online and translated into as many languages as possible. The Classification Task Force will develop a diagnostic manual focusing on specific common electro-clinical syndromes to facilitate diagnosis and appropriate management around the world. We encourage you to read more; please see the Commission's report in *Epilepsia* which is due out online in the upcoming weeks.

#### A Report from the Commission on Epidemiology

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

A new ILAE 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 Hauser (Past Chair), Ley Sander (Treasurer),



E Beghi

D Hesdorffer

Charles Newton (Secretary), Torbjorn Tomson (Educational Officer), Giancarlo Logroscino (Information Officer), Ding Ding, and Marco Medina (Executive Committee Liaison). Commission tasks for this term reflect the goals of epidemiology and follow in the wake of the previous Commission (2001-2005). They will be performed in collaboration with other ILAE Commissions, including Classification, Diagnostic Methods, Education, Pediatrics, and Psychobiology. The action plan of the Epidemiology Commission for the 2009-2013 term includes the following activities:

- The completion of a position paper outlining standard definitions, study designs, and instruments to improve the quality of epidemiological research in epilepsy and to facilitate comparison of the burden of epilepsy worldwide. The Commission will offer support to epidemiologists as they begin to use this document;
- 2) Further work on mortality in epilepsy to include: completion of a pooled analysis of the available evidence on the risk factors for sudden unexplained death (SUDEP); identification of causes of death in epilepsy, separating those which are epilepsy risk factors from those which are not; and identification of risk factors for preventable causes of death in epilepsy and potential prevention strategies to reduce the burden of preventable mortality in epilepsy;
- 3) Work on comorbidity in epilepsy to determine and describe the scope of epilepsy comorbidies (psychiatric, neurological, other somatic and cognitive), to clarify whenever possible the time order of associations, to determine the impact of comorbidities on the prognosis of epilepsy, and to determine which (if any) comorbidities are specific to epilepsy among the neurological disorders that have known comorbidities;
- Development of a Web-based database for the assessment of the reliability of the newly developed classifications of the epilepsies; and
- 5) Development of a definition of status epilepticus for use in epidemiological studies.

#### A Report from the Commission on Neuropsychobiology

Andres M Kanner, MD and Marco Mula, MD PhD, Co-Chairs

Recent population-based studies have shown that psychiatric comorbidities are relatively frequent in patients with epilepsy (PWE), as one in every three patients have experienced a psychiatric disorder in their lifetime. Despite the high prevalence of psychiatric disorders, they remain undetected and untreated in a majority of patients. Accordingly, the three principal aims of the new Neuropsychobiology Commission are:

- To provide clinicians with user-friendly screening instruments to identify the most frequent psychiatric disorders seen in PWE (e.g., mood, anxiety and attention deficit hyperactivity disorders).
- To provide treatment protocols for these conditions that can be administered by nonpsychiatrists and psychiatrists, alike, taking into account the available resources in the various regions in the world.
- To provide user-friendly protocols of psychiatric evaluations and treatment protocols in specific groups of PWE including: a) pediatric and



A Kanner



M Mula

elderly patients; b) patients undergoing a pre-surgical evaluation; c) patients with cognitive developmental delay.

To achieve these goals, the Commission has created nine Task Forces, integrated by adult and pediatric neurologists and psychiatrists from all four continents. The various Task Forces will work in conjunction with Task Forces from other Commissions as well as with the Regional Commissions. The Task Forces are organized in the following areas: mood and anxiety disorders; intellectual disabilities in adults with epilepsy; treatment strategies; psychiatric aspects of epilepsy surgery; psychogenic non-epileptic seizures; child neuropsychiatry; psychoses in epilepsy; disabling epilepsy and education.

Continued on page 8

(continued from page 7)

#### A Report from the Commission on Pediatrics

Douglas Nordli, MD and Perrine Plouin, MD, Co-Chairs

The Commission on Pediatrics has been actively working on its objectives for the next four years. One theme that will run through its efforts will be an emphasis on infancy. The main goals for this period are the following:

 Develop electronic educational materials that emphasize optimal care of children with



P Plouin and D Nordli

**epilepsy.** This content will be specifically designed to aid colleagues in developing countries and will be developed together with the Commission on Education.

- 2) Create guidelines for the evaluation of infants with epilepsy that are appropriate for both developing and developed countries. These guidelines will be a continuation of the algorithm created for diagnosis and treatment of neonatal seizures in developing countries. These guidelines will include recommendations for genetic testing, metabolic investigations, electrophysiological studies, imaging and screening for autism in infants in collaboration with the Autism Task Force.
- Develop materials to aid in transition of adolescents to adult practitioners. We will produce a document with specific recommendations to aid transition of care.
- 4) Expand an infants' registry and consider multi-center comparative drug trials. Several registries on infantile epilepsy cases already exist. The first step should be to unify the data from these various registries. In a second step, the feasibility of conducting multi-center comparative drug trials in selected epilepsy syndromes should be explored.
- 5) Create an ILAE-AS Epilepsy-Autism Task Force. We need to establish a bridge of communication between Autism Speaks (AS) and ILAE who have the common goals to promote services and education. We will coordinate educational programs on autism spectrum disorders (ASD) and epilepsy and encourage studies on issues common to ASD and epilepsy.
- 6) Hold workshops to exchange information. We will organize four translational meetings covering the following topics: classification and epidemiology, neurobiology and genetics, animal models and neuropathology, and treatment. We will create appropriate guidelines from these workshops. At the end of the four years we hope to have an entirely new concept of children who have epilepsy and autism and how to treat the two conditions.
- 7) Task Force for Pediatric Epilepsy Surgery This Task Force will continue the work on the evaluation of epilepsy surgery in children worldwide.

#### A Report from the Commission on Genetics

#### Samuel F Berkovic, MD, Chair

Membership: Sam Berkovic (Australia, Chair), Peter De Jonghe (Belgium), Alica Goldman (USA), Shinichi Hirose (Japan), Marcello Kauffman (Argentina), Dan Lowenstein (USA), Carla Marini (Italy), Ruth Ottman (USA), Thomas Sander (Germany), Sanjay Sisodiya (UK), Nigel Tan (Singapore), Michel Baulac (France, EC Liaison)

Epilepsy genetics is at a very exciting and challenging phase. The new Commission had a very successful first meeting at the American Epilepsy Society meeting in Boston this past December. An Action Plan has been developed to address the critical issues.



S Berkovic

First we aim to improve the genetic literacy within the professional epilepsy community. The explosion of advances in the technology, data and clinical implications in this field can be bewildering to the non-expert. To keep our colleagues up to date with these issues, especially as they relate to epilepsy, we will create a series of educational measures including courses and practical information on the ILAE Web site. These additions should enable the practicing epileptologist to remain abreast of recent developments, particularly those of direct clinical relevance.

Second we will improve general education about epilepsy genetics. Sadly, genetic issues remain a subject that can result in discrimination and stigma in the community. Through education, emphasizing the direct benefits of genetic advances, we will change these negative misperceptions. We will coordinate this effort closely with the IBE and the Global Campaign.

Third, the Commission will act as a facilitator of a very large International Consortium to address the molecular basis of common epilepsies with complex inheritance. At the time of this writing no Genome Wide Association Studies of epilepsy have been published, and unpublished data are negative and/or underpowered. By bringing together a very large consortium under the banner of the ILAE we hope to accelerate major advances in this area. Importantly, the Commission will facilitate the Consortium and not run it. The Consortium will be open to all and a governance structure is being developed. Epilepsy colleagues interested in participating should watch for announcements on the ILAE Web site or contact the Commission Chair (s.berkovic@unimelb.edu.au) to register their interest.

#### A Report from the Neurobiology Commission

Astrid Nehliq, PhD and Jeffrey Noebels, MD, PhD, Co-Chairs

The ILAE Neurobiology Commission is an

international group of scientific leaders representing all ILAE regions whose primary mission is to advance research on the causes and basic mechanisms of the epilepsies in order to improve medical therapy. This mission is accomplished in part by fostering the research training of young investigators around the world through the organization and support of regional and global workshops, and by encouraging their scientific participation in ILAE Congresses. The Workshop on Neurobiology of Epilepsy (WONOEP) is the principal forum, and is held in conjunction with the biannual ILAE Congress. WONOEP is an intensive four day workshop where junior and senior scientists ioin to explore a selected theme in experimental epilepsy research, build collaborative bridges among international laboratories experienced in multidisciplinary technical approaches, and contribute their findings and expertise in published proceedings.

To accelerate the flow of laboratory discoveries into clinically useful therapies, the Commission will focus in the coming years on translational research approaches that combine the advanced crosstraining of clinical and basic epileptologists in areas

linking human and experimental neurobiology, pharmacology, imaging and genetics. The Commission also provides technical and financial support for outstanding regional activities, including the Epilepsy Summer Courses at San Servolo in Venice and the Gordon Conference on Epilepsy. These events are designed to bring together clinical and laboratory researchers from inside and outside the field of epilepsy to share some of the most recent discoveries, to discuss how these discoveries can be practically applied, and to stimulate new approaches to epilepsy therapy.



A Nehlig



# ILAE Epilepsy Academy Announces Courses

The European Epilepsy Academy, being a part of the European structure of the International League Against Epilepsy (ILAE), is a nonprofit educational association which aims to improve epileptological knowledge and consequently the quality of care throughout Europe. There are two regional onsite courses scheduled for 2010.

The 4th Baltic Sea Summer School on Epilepsy will be organized in Granavollen, Norway, from 6 to 1 June 2010. The BSSSE is primarily addressed to medical postgraduates and junior researchers (age up to 40) with a special clinical/scientific interest in epilepsy. More information and online application (deadline 10 April 2010) now available under http://www.epilepsyacademy.org, or contact Petra Novotny, EUREPA, petra@epilepsy-academy.org. The 4th Migrating Course on Epilepsy will take place in Serock, Poland, from 15 to 22 August 2010. This course is targeted to specialists at the second and third level of epilepsy care. Online application is now possible. The deadline is 1 February 2010. Please see http://www.epilepsy-academy.org, or e-mail to Petra Novotny, EUREPA, petra@epilepsy-academy.org.

Both courses are organized in cooperation between the Commission on European Affairs of the ILAE and EUREPA, the European Epilepsy Academy. They are clinically oriented and focused on the comprehensive aspects of diagnosis and treatment of epilepsy. The BSSSE in addition features encouragement of research interests. The format of both courses involves combinations of lectures and interactive group work, with tutored case-oriented studies in an informal and open atmosphere.

# Education Programs for People with Epilepsy (PWE)

The curricular education programs listed below are addressed to people with the condition of epilepsy and their families. These programs are delivered by trained professionals in the field of epilepsy and can be run in different settings, like in clinics, epilepsy centers, homes for handicapped people or private practices.

- Educational programs for people with epilepsy under the auspices of EUREPA: MOSES and Famoses
- Programs for Healthcare Professionals (HCPs) (in development)

- Flip & Flap Schulungsprogramm für Kinder und Jugendliche mit Epilepsie und ihre Eltern [in German]
- Pepe Psycho-Edukatives
  Programm Epilepsie [in German] for people with additional learning disability or mental retardation
- The Penguin A Teaching Plan for Children with Epilepsy link to article by A Amdam, B Langslet, T A Holmseth in: M Pfäfflin et al, Comprehensive Care for people with epilepsy. John Libbey. 2001. (information at firmapost@desitin.no). For more information on these

programs go to http://www.epilepsyacademy.org/homepage/de/175.html.

### Topic-Oriented Commission Reports

(continued from page 8)

### Priorities and Action Plan for the Education Commission

#### Chong Tin Tan, Chair

The Education Commission, working under the new Strategic Plan, has developed a broad agenda for providing appropriate educational programs that are designed to meet the needs of the specialists and nonspecialists who care for people who have epilepsy. The following is an outline of the activities that will be the focus of our activity in the next four years.

#### 1) The Regional Academies

We believe that the educational effort should be region-based. As each region is able to appreciate the needs in its geographical area and can use resources within the region, the education



C Tin Tan

program is likely to be more cost-effective. The first priority is thus to strengthen and promote the further development of regional epilepsy academies in all parts of the world. Right now, Europe, Asia and Latin America have established epilepsy academies. There are differences in the emphasis of education activities in each region. In Europe, the focus is on migrating courses in Eastern Europe, San Servolo Summer School and distance education. In Asia, it is the workshops, fellowships and EEG certification examinations. In North America, it is the outreach to the Caribbean; and in Latin America, summer school (LASSE), workshops and distance education.

Dr Hasan Hosny has been identified as the main education liaison in the Eastern Mediterranean Commission (CEMA). The education activities proposed include the CEMA congress, education course during the PanArab Medical Association Congress, joint education activities by CEMA and the local chapters, and development of a speaker's bureau list. CEMA also felt the need to create an education Task Force for countries with the least resources.

There have been various African education initiatives including that of the Francophone, Lusaphone and Anglophone activities. There are discussions on establishing a coordinating body for Africa to oversee the Global Campaign and education efforts within that region. The Education Commission proposes to organize "summer schools" to train key national epilepsy care leaders from the different language regions in Africa.

2) Workshops and Symposiums by Topic-Orientated Commissions Education is an important role also of the topic-orientated commissions as they have a clear view of the latest developments in their area. The educational agenda of these commissions is often met by symposia and workshops embedded in the main program or as pre-congress workshops during the international or regional epilepsy congresses.

To develop symposia and workshops, each commission is encouraged to contact the Chairs of the Scientific Advisory Committee (SAC) of the relevant congresses, and submit their specific proposals.

#### 3) Distance Learning Courses

The distance learning courses provided over the Internet are a valuable educational activity appreciated by many of the past students. This effort has been led by VIREPA. One of the most valuable assets is the group of enthusiastic tutors. A sub-commission headed by Walter van Emde Boas has been set up to supervise and develop distance learning. There are two practical challenges: first, how to reduce cost and ensure long term financial viability, and second, to ensure the distance education is under the direction of the ILAE. In future, the distance education will be organized under the Education Commission, which aims to grow and expand this important activity.

#### 4) Web-based Information Resources

A major goal of the Strategic Plan is reaching out to health professionals worldwide and making it easier for them to access practical guidelines. We also must capture and use educational materials generated from the international and regional meetings. We will set up a sub-commission for Web-based information resources, with members from different topic-based commissions and those skillful with IT. The Webbased open access information and knowledge portals will make available the educational materials captured in the ILAE-related congresses and meetings, guidelines, consensus and other e-learning resources.

#### 5) ILAE Textbook

This will be an online, open-access, comprehensive textbook on epilepsy, serving as an authoritative encyclopedia for healthcare professionals all over the world. The main features will be: open access, comprehensive coverage, global perspective, authoritative, use of simple English by epilepsy specialists from all parts of the world for clinical practitioners, integrated with other ILAE consensus, recommendations and guidelines. It will be updated on a regular basis. This will improve the resources for physicians and other healthcare professionals, particularly from resource-deprived areas, increase the participation of ILAE members, and enhance the image of ILAE among the medical and scientific community at large. Dr SH Lim from Singapore has been appointed as Editor and a member of the Commission for this task.

# A Special Partnership

A s the recently elected President of the International Bureau for Epilepsy (IBE), I would like to acknowledge the long-standing commitment between IBE and ILAE to work together to improve the lives of people with epilepsy globally. I commend the great work that ILAE does, especially

in the areas of education, training and research. This relationship has continued to grow and some significant joint projects have emeraed such as the Global Campaian Against Epilepsy (GCAE) which is now in its fourteenth year. It is my intention to have a much more hands-on, personal role in the activities of the GCAE. As many of you will be aware, I have been a staunch supporter of the GCAE over the years and believe that there is still a lot more that the IBE and ILAE can achieve through it. At times, I think the achievements of the GCAE have not been highlighted to the full and it is my hope that a areat deal more can be achieved through the GCAE; particularly in Eastern and Central Europe but also in all areas of the developing world.



Mike Glynn

get rid of the term "epileptic" as a description for a person with epilepsy. Considerable progress was made in this area some vears ago and, in the developed world at least, the term seemed largely to disappear. However, recently there has been an alarming proliferation amona journalists of the use of this appalling term. I would like to start a new anti-stigma campaign. We are currently beginning to compile research on the subject and look forward to generating momentum for this campaian so that we can aet rid of the use of this word as a noun once and for all.

The special relationship between the League and the Bureau is one that is much admired and often envied by the medical and lay representatives of many other conditions. We should never take it for granted. On behalf of myself and the members of the IBE International Executive Committee, I would like to thank ILAE for their support and cooperation over the years and I look forward to continue working closely with ILAE on future projects.

One similar

obiective both

ILAE and IBE

share is the

determination

epilepsy-related

stiama. Manv

of you may be

time, l've

campaigned

considerably to

aware that over

to eliminate





# Epilepsy Meetings of Interest

Tenth Eilat Conference on New Antiepileptic Drugs (Eilat X) Isrotel Royal Beach Hotel, Eilat, Israel 25 – 29 April 2010

25 — 29 April 2010 http://www.eilat-aeds.com

#### Progressive Myoclonus Epilepsies: PME's In The New Millennium Venice, San Servolo

28 April — 1 May 2010 http://www.fondazione-mariani.org

#### 4th International Conference of Biomarkers in Chronic Diseases

Diabetes, Obesity & Cardiovascular Diseases Riyadh, Saudi Arabia 4 — 6 May 2010 http://biomark.ksu.edu.sa

### 15th International Endoscopic Neurosurgery Workshop

Ghent, Belgium 9 — 12 May 2010 http://www.neuroendoscopy.org Epileptology Course 17 - 19 May Quail Hollow Resort, Paynesville, OH USA 3rd International Epilepsy Colloquium 19 - 22 May Renaissance Cleveland Hotel, Cleveland OH USA http://casemed.case.edu/cme

4th Baltic Sea Summer School on Epilepsy Granavollen, Norway 6 – 11 June 2010 http://www.epilepsy-academy.org email Petra Novotny, EUREPA: petra@epilepsy-academy.org

#### 2010 San Servolo Summer School

Advanced International Course: From Basic Knowledge and Clinical Trials to Rational Prescribing in Epilepsy San Servolo, Italy 18 – 19 July 2010 www.epilepsy-academy.org

#### 20th Meeting of the European Neurological Society Berlin, Germany

19 — 23 June 2010 www.ensinfo.org

#### 7th Forum of European Neuroscience

Amsterdam RAI Convention Center, Amsterdam, The Netherlands 3 – 7 July 2010 http://forum.fens.org/2010

#### 4th Migrating Course on Epilepsy

Serock, Poland 15 – 22 August 2010 http://www.epilepsy-academy.org or email to Petra Novotny, EUREPA, petra@epilepsy-academy.org

#### **Epilepsy and Depressive Disorders**

The Westin Chicago River North Hotel, Chicago, USA 12 — 13 September 2010 www.epilepsyanddepressivedisorders.com

#### 2010 Epilepsy Symposia

Intercontinental Hotel & Bank of American Conference Center, Cleveland, OH 2 – 6 October 2010 http://www.clevelandclinicmed.com

# The ILAE Web Site — www.ILAE.org

In the past few years, the ILAE Web site has grown steadily and now plays a key role in communicating League activities. The Web site is managed by the Information Officer with the help of the Web Site Task Force. The site has three main roles:

- To present information about ILAE personnel, structure and purpose;
- To convey information about epilepsy for the benefit of ILAE members (including interactive areas);
- To assist in ILAE administrative activities.

The site continues to develop. New content is always being developed. Recent additions include the updated Classification and Terminology report that allowed comments to be posted for a period of time, Centenary meeting historical panels, a new member database and easier access to regional commission information. Coming soon is an update to the Bibliography.

The new member database is called mvILAE and allows individual members to maintain their own contact information on the Web site. Currently myILAE grants vou the ability to: Purchase publication/ subscription in the Online Store and review your member record and transaction history. Regularly updating your contact information allows the League to keep you up to date on worldwide activities. In the near future a social networking component will be added to allow easier communication and sharing of documents for the Regional Commissions and Topic-Oriented Commissions.

Additional content is welcome on any of the pages of this Web site. Feel free to contact Information Officer Ed Bertram at ehb2z@virginia.edu to discuss submitting documents.

#### About the ILAE

This area contains information about the Executive Committee, Commissions and Task Forces, the ILAE Constitution and Bylaws, and the current Strategic Plan.

# ILAE Resource Central

This area contains resources for members. Among the entries are:

 Epilepsy Bibliography. This is a list of Books and Monographs published in the field of epilepsy. It is compiled by



Dr Fukuyama and is in a fully searchable format.

- A worldwide AED Database, originally compiled by Bob Fisher, allows members to view a comprehensive list of antiepileptic drugs (with generic and proprietary names) that are available around the world. The database can be searched by brand name, generic name and/or in which country certain medications can be found.
- ILAE Worldwide Resource Directory, a searchable database of the EIC collection of 1,500 epilepsy-related publications and videos held in Zurich. This database is updated regularly in collaboration with the EIC. Almost all of the videos and documents have now been copied into digital format.
- Epilepsy Brochures Fifteen brochures about epilepsy have been copied and put online; some of the brochures have been translated into four languages. It is planned to post further selected items and eventually to have 50-100 documents on the site.
- Global Campaign section presents details of the ILAE/WHO/IBE Global Campaign and links to the WHO Web site.
- Guidelines Recently published ILAE guidelines are posted here as are National Guidelines shared by chapters.
- A links section provides links to other professional organizations and the Epilepsy Partners section provides links to ILAE's partners.

# Chapters and Regions

This area contains information about Regional Commissions, ILAE chapters worldwide and their activities.

- Details of ILAE national chapters, their officers and council members. There are links to the chapter Web site (where available) and e-mail contact details.
- The annual reports of individual chapters are also posted when available.
- Map showing geographic location of each chapter, with a clickable search facility.
- Access for chapters to update their information.

### **Education**

This section provides easy links to ILAE congresses, regional and chaptersponsored congresses and meetings, Webbased education through EUREPA, VIREPA and other educational programs.

# Classification and Terminology

The Classification and Terminology Commission posted a draft of the revised terminology and concepts for organization of the epilepsies in 2009. The final report will be posted in 2010.

#### **Bookstore**

ILAE invites book publishers to advertise on these pages to let you know about the latest books in the epilepsy field.

### Commission Reports and Activities

These pages allow Regional and Topic-Oriented Commissions to publish reports of their activities.

# Meeting Proceedings and Position Papers

In these pages, you will find meeting proceedings provided by regions and chapters, as well as Position Statements and Guidelines submitted by regions and chapters.

### **Publications Section**

This area contains information about ILAE publications:

- The current edition of the ILAE newsletter, *Epigraph*.
- Information about *Epilepsia* and links to the journal Web site.
- A subscription area for discounted subscriptions available to ILAE members for *Epilepsia* and six other epilepsy journals.
- The most recent ILAE Annual Report.

### **Archive Section**

This area contains archived copies of recent ILAE documents:

- Non-current copies of *Epigraph* (from 1999).
- Annual reports.
- Awards section with details of ILAE awards and the recipients, since 1999, of the following awards: Ambassador, Lifetime Achievement, The Michael Prize, Social Achievement, Young Investigators Award and the new Morris-Coole Prize.
- The new ILAE Archive is a searchable index of minutes, reports, programs, scientific papers and correspondence.

# **Contact Details**

This section contains contact information for the Hartford and Dublin offices and personnel.

#### Farewells

This new addition to the Web site provides space to publicly acknowledge the passing of those actively involved in the ILAE or the field of epilepsy. Submission instructions are on the Web site.

# League Initiatives and Projects

Initiatives and projects of the League, via its regions and chapters, are reported here.

# Upcoming 2010 Congresses

### 27 June - 1 July 2010

**9th European Congress on Epileptology** Rhodes, Greece



The 9th European Congress on Epileptology aims to reflect the current momentum in epileptology created by the challenge to translate the recent advances in basic neuroscience research, the emerging pathophysiology concepts and the powerful new diagnostic tools (from molecular probes to non-invasive brain imaging) into better epilepsy patient care.

The scientific program will feature interesting and varied topics that encompass recent scientific developments and will allow those working in all fields of epilepsy to update their knowledge. One of the primary aims of this Congress is to include the latest pediatric research and we are delighted that the European Society of Pediatric Neurology agreed to propose sessions to be included in the program. In addition, whenever possible, basic and clinical science is being combined.

# 1 - 4 August 2010

6th Latin American Congress on Epilepsy (6° Congreso Latinoamericano de Epilepsia)

Cartagena, Columbia



It is with great pleasure that we extend this invitation to the 6th Latin American Congress on Epilepsy. The Congress, held under the auspices of the International League Against Epilepsy and the International Bureau for Epilepsy, will take place in Cartagena

between the 1st and the 4th of August 2010.

We are proud to present a varied and interesting scientific program that includes topics of high appeal presented by a wide range of speakers from the region and several outstanding international speakers. The interaction between colleagues and the presentation of recent research will be an important part of the Congress. The ALADE (Academia Latinoamericana de Epilepsia de la ILAE) didactic courses and the discussion groups will have a more practical focus.

# 25 - 27 August 2010

#### 12th European Conference on Epilepsy and Society Porto, Portuaal



On behalf of the Organizing Committee, we are pleased to invite you to Porto to attend the 12th European Conference on Epilepsy and Society taking place from the 25th to the 27th of August 2010.

We look forward to welcoming you to the attractive city of Porto for what is going to be an excellent gathering of wonderful people. In this way

we believe we will not only increase our knowledge and understanding of epilepsy, but we will also fulfill the common goals of the International Bureau for Epilepsy.

# 21 – 24 October 2010

8th Asian and Oceanian Epilepsy Congress Melbourne, Australia



On behalf of the Scientific Organizing Committee, it gives us great pleasure to invite you to the 8th Asian & Oceanian Epilepsy Congress (AOEC) which will take place in the exciting city of Melbourne, Australia from 21 to 24 October 2010. This Congress has been organized by the

regional organizations of the International League Against Epilepsy and the International Bureau for Epilepsy.

# 28 August – 1 September 2011

29th International Epilepsy Congress Rome, Italy



More information available on **www.ilae.org** later this year



is coordinated by Edward Bertram with the assistance of Cheryl-Ann Tubby in the ILAE Hartford office. The print edition is kindly sponsored by an unrestricted educational grant from Pfizer.

All communications should be directed to Cheryl-Ann Tubby at epigraph@ilae.org, or by telephone 860.586.7547, or fax 860.586.7550

Printed in Great Britain by Burleigh Press, Bristol BS2 0YA www.burleighpress.co.uk