## INTERNATIONAL LEAGUE AGAINST EPILEPSY

### Editorial



Epigraph. The issue of Epigraph. The issue is being circulated mainly in the conference bags of the 2006 regional ILAE conferences and has a

different purpose from the three 2006 online issues of *Epigraph*. The online issues are sent by email to all ILAE members and have a newsletter function and format — and on page 8 there is an article which provides more details on this new ILAE initiative. In contrast, this print edition is intended primarily to give an overview of the ILAE and some of its activities. Although hopefully all ILAE members will learn something from the issue, it is designed particularly for new members and also for the non-members attending the ILAE conferences, and for those who have not had much contact with the ILAE before.

ILAE is an organisation which was founded in 1909 and which has in recent years expanded in size and in the range of its activities. There are now 96 chapters and over 15,000 members around the world. The purpose and structure of the ILAE and details of some of the ILAE activities are featured on different pages of this *Continued on page 2* 

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### President's Message

Greetings As of the last evening of August 2005, a new team of officers has taken charge of the affairs of the International League Against Epilepsy (ILAE). The current Executive Committee combines the aspects of experience and innovation. In addition to the Past President, Giuliano Avanzini, who has the constitutional role of guaranteeing continuity, two of the elected officers, Second Vice President Fred Andermann and

Treasurer Martin Brodie, have served on the previous Executive Committee (EC). Personally I was not on the past Executive, but know the ILAE administration well from my time as Secretary General (1993-2001). Two new people in the group, Emilio Perucca and Nico Moshé, have taken responsibility as First Vice President and Secretary General, respectively. Simon Shorvon continues as Information Officer, and he and Phil Schwartzkroin were appointed as the new joint Editorsin-Chief of *Epilepsia* on the retirement of Bob Fisher in December 2005.

With the Executive Committee in place, we have already been hard at work for the League. One of my two main focuses for my presidency is on education, which is the clue for any development. The ambition with this priority is no less and no more than the implementation of an educational system in the field of epilepsy which is the best and unparalleled by any other field of medicine. Is this obtainable at all? Yes, it is, and we are even well advanced on our way to get it achieved. Not only do we already have multiple educational activities, we are also well under way to put them into a system. The components are

- A modular curriculum to obtain certification as an epileptologist.
- Summer Schools and similar educational courses where a group of students can interact with a highly distinguished faculty of experts over at least one entire week, in an ambience which facilitates study.
- A group of trainers in Europe, and recently Africa, who have participated in a train-the-trainers course.
- A series of distance education modules in fields which lend themselves to this teaching format.



Peter Wolf President, ILAE

 An "educational network" of centres and institutions offering on-site training in parts of the curriculum.

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- Specific educational conferences for the primary and secondary levels of health care, especially in countries with little developed specialisation.
- Special educational activities for professionals allied with medicine (PAM).

Most of these components have been developed in Europe where the European Epilepsy Academy (Eurepa) has

been active since 1996; others apply to Asia/Oceania with their active regional academy ASEPA. EUREPA via a Francophone Section has reached out to the Frenchspeaking countries in West and Central Africa, and a Lusophone Section is taking shape as a joint effort of the ILAE Chapters of Brasil and Portugal with EUREPA.

While at the Annual Meeting of the American Epilepsy Society last December, I met with their Education Committee to build a bridge to bring our experiences together. Our global educational program would require a "Faculty of 500" and quite a few AES members had already expressed their readiness to make themselves available as teachers and tutors.

I have attended the meeting of the Commission on European Affairs (CEA) who again agreed to support educational activities provided through the EuREPA channels to Africa (francophone and lusophone countries). The Commission expressed hopes to see similar activities from the ILAE. They are working on a draft of rules of procedure for commissions and have been asked to submit it to the EC when it is ready. New educational projects in Europe comprise an annual "Migrating Course" for doctors working on the 2nd and 3rd level in the Eastern European countries, and a Baltic Sea Summer School for young future epileptologists as an initiative of the three Scandinavian Chapters.

There is quite a positive echo to education being priority, and people have expressed their interest in participating in the "Faculty of 500". This is one of the issues for which it is important to have the International Academy in place as soon as possible because the Faculty.

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#### President's Message

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In Helsinki, the first distance education course on EEG in epilepsy will be launched. It is designed as the first of two sequential courses (basic and advanced) and basic training in EEG is requested for participation. This is expected to be the last distance education course which is developed by EuREPA and out of Europe, with financial support of the CEA. International taskforces will be established for the development of other courses, with *Imaging in Epilepsy* and *Clinical Pharmacology of AEDs* as the next topics to be addressed.

### The Regions

More changes, however, are ahead: Paradoxically as it seems, the expansion of the ILAE to now almost 100 Chapters, has had the consequence that fewer and fewer regions are represented on the Executive. The EC from 1997-2001 had officers from Asia, Europe, Latin America and North America, the last EC had no Asian member, and now we have come to a mere European / North American Executive. The reason probably is twofold: that Europe is the largest region, with about 40% of all chapters, including many relatively large chapters and therefore representing the majority of votes; and that our internal communication is not yet good enough to ensure global perception of all important contributions to our progress, especially those of primarily regional character, contributions which would most probably be reflected in the outcome of the elections if they were better known.

I am pleased that it was a European Chapter that proposed an amendment of our constitution, which was accepted with broad agreement, to open the EC up for at least those regions who are fully operative, to elect an additional Vice President in case they have nobody on the EC. The "Danish Amendment" is an expression of a strong spirit of worldwide friendship, mutual respect and alobal commitment which we all in the ILAE have reason to be proud of. The wording of the amendment makes it clear that we will not be moving from a global organisation. with a central administration interacting with the chapters, to a multiregional network. But the experiences and wisdom created in the regions by their commissions will be integrated to enrich and improve our alobal agenda.

The new EC, during its first meeting on September 1, has already defined criteria to consider a region as "fully operative", and these have been brought to the attention of the regions who right now are not present on the EC. The Asia and Oceanian region has already fulfilled the criteria and is presently voting for an additional Vice President.

### **Global Campaign**

The end-of-term reports of all outgoing Commissions but Epidemiology have meantime been received and several of them required correspondence with the outgoing Chairs, which is not terminated in all instances. One typical situation is that subcommissions and working groups have not terminated ongoing activities, and I would like to consult with the EC on the best way of dealing with this. My proposal is to give these groups deadlines to finish their business as "taskforces," and thereafter consider them dissolved.

The old Commission on Asian and Oceanian Affairs is still conducting the business of the region as the new Commission can only be finalized after the elections of the additional Vice President from that region have been accomplished. Nonetheless, they have produced a report for this meeting which documents their ongoing activity, especially in the field of education. I have tried to keep a helpful eye on the transition of the Global Campaign Management, where the involvement of the regions is not yet satisfactory. Thanks to the activities of Giuliano Avanzini, Phil Lee and Hanneke de Boer, the agreement with the WHO re the consultant status of Dr. Prilipko seems now to be satisfactory.

Meetings of the SAC and IOC for the congresses in Helsinki and Singapore, respectively, showed good progress with both. For the Guatemala congress, a brainstorm for the development of the Caribbean is being planned on September 9, 2006, and I am inviting participants from the territories around the Gulf of Mexico and the Caribbean. This is an ILAE initiative as a regional contribution to the GCAE and on the background of our priorities.

We have a lot to do over the next four years and the involvement of our membership will be a key ingredient to the success of the League and its pursuits.

Peter Liff

#### Editorial

(continued from page 1)

issue. Included are an ILAE 'primer' and articles on its national chapters, the composition of the Executive Committee and commissions and Taskforces, the Global Campaign, the ILAE regional and international conferences, the ILAE Web site, the online newsletter *Epigraph* and the ILAE's scientific journal *Epilepsia*. The most important new initiative of the ILAE is to promote epilepsy education — and Peter Wolf, ILAE president, outlines how he sees this being achieved in his presidential message.

The information provided in this issue of *Epigraph* is because of the limitations of space a brief outline only — and certainly does not do justice to the depth and quality of the work of the League in many areas. Nevertheless, hopefully the issue provides at least a flavour of the ILAE and will encourage all of you to contribute to and to take an active part in its activities. In almost every aspect of the League's work, the contribution of new members is needed and new people bring new ideas and new energy. The organisation is powered by the voluntary work of its members and officers throughout the world: without this work there would be no ILAE. The benefits of membership of ILAE are listed on page 5 with details on how to join. Membership is through the national chapters and those interested should contact the secretary of the national chapter (contact details are on the chapter pages of the ILAE Web site www.ilae.org).

Simon Shorvon Editor*, Epigraph* 

### How to Join the International League Against Epilepsy

The ILAE is a federation of 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 Commissions/Taskforces
- Access to the online ILAE Discussion Group

Of greatest importance, is the fact that membership strengthens the authority of ILAE national and internationally in its mission to influence and improve epilepsy care worldwide. Your membership counts.

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 — the contact addresses are listed on the ILAE Web site www.ilae.org.

## International League Against Epilepsy: A Primer

he ILAE is an international nonprofit organisation registered in the United States, and 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 in size and influence in recent years. From its earliest years, it has been organised into national chapters and currently there are chapters in 96 countries and over 15,000 members worldwide.

The mission of the ILAE is to work towards a world where no person's life is limited by Epilepsy. Its goals are to promote 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 Website at www.ilae.org.

#### **Executive Committee**

The ILAE is overseen by an Executive committee, currently of eleven persons (current members in brackets). The President (Peter Wolf) is elected by a ballot of national chapters for a 4 year term. The Secretary General (S. Moshé), Treasurer (M. Brodie) and two Vice Presidents (E. Perucca and F. Andermann) are also elected by a ballot of national chapters for a 4 year term. The Information officer (S. Shorvon) and the Editors-in-Chief of Epilepsia (P. Schwartzkroin, S. Shorvon) are appointed by the President and the Executive Committee. The past president (G. Avanzini) serves for a 4 year term. The President (S. Lund), Secretary General (E. Hargis) and Treasurer (M. Glynne) of the sister organisation, the International Bureau Against Epilepsy (IBE), are exofficio members of the Executive Committee. In the future, there will be representatives from some regions also elected onto 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 16 articles, and the bylaws has fourteen sections, and these cover the objectives, membership, governance and the range of ILAE activities and its structure. The Constitution can be amended only at the General Assembly of the ILAE.

### **National Chapters**

Each national chapter has its own constitution and 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, but generally speaking membership is open to any doctor and health professional interested in epilepsy.

There are currently 96 chapters in the ILAE, which is the greatest number in its history. The largest is the American chapter with 1,745 voting members and the smallest are the Singapore chapter with 12 and the Moldovian chapter with six. The role of the national chapters is generally to establish and maintain good communication between persons active in the field of epilepsy, promote publications in the field of epilepsy, organise 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, South America, Europe, Eastern Mediterranean, Asia and Oceania, 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 and chairpersons are: European Commission (M. Baulac), Asian and Oceanian Commission (S.H. Lim), North American Commission (J. Noebels), Latin American Commission (J. Moctezuma), Eastern Mediterranean Commission (B. Yaqub).

### ILAE Commissions and Taskforces

In every four year term, the President and the Executive Committee appoint Commissions and Taskforces to carry out work for the ILAE. These bodies involve individual members transnationally. On page 5, there is an article providing more details about the role and constitution of the current Commissions and Taskforces and a list of the current groups and their Chairmen.

### Administrative Offices

The ILAE has two administrative offices. The Financial office is in Hartford and the ILAE HQ is in Brussels. 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 (Administrative Director), Delphine Sartieux (Assistant Administrative Director), Donna Cunard (Finance Director), Christer Osterling (Web site Project Manager), Nele Delvolder (Membership Services).

### ILAE Conferences and the Office of the IDM

ILAE holds a global scientific conference (Epilepsy International Congress) once every two years. Each region holds a regional scientific conference every two years, in the years when there is no global conference, and most national chapters hold 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 organised

Homes, 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 educative activities and to identifying on a worldwide basis the needs of those with epilepsy. The third phase was launched this year and is focused on special projects in different parts of the world and on assisting health care 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 Blackwell and edited by an Editor-in-Chief (or as currently two joint Editors-in-Chief; P. Schwartzkroin, S. Shorvon) who appoint an editorial board and associate editors. *Epilepsia* was started in 1909, and currently is published monthly. It has an annual turnover of \$1.4 dollars, a subscription base of 10649 (consortia, individual and institutional), and in 2005 399,814 articles were downloaded from its online hosts.

### ILAE Web Site and Epigraph

Ten years ago, the ILAE launched its own newsletter *Epigraph* to be sent to all individual members. It was initially sent out 2-3 times a year, but from 2006 4 issues a year will be published — three online and one 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. Four years ago, ILAE also launched a Web site (www.ilae.org). This has grown in size and complexity and in 2005 there were 249,911 visits. *Epigraph* 

Continued on page 4

by its own conference organiser (Richard

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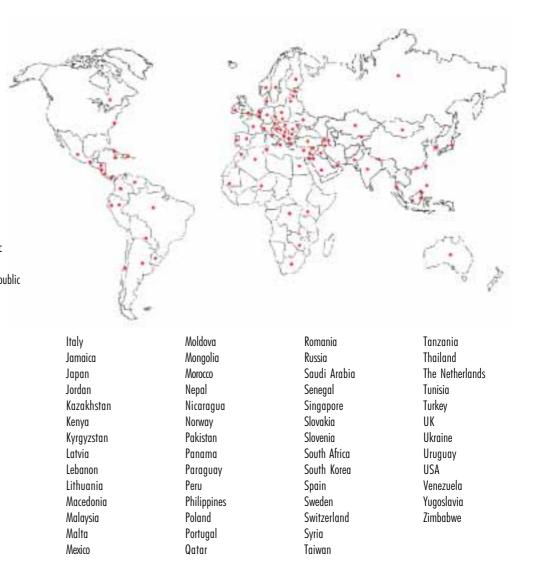
### ILAE Chapters

he International League Against Epilepsy (ILAE) approved four new national chapters at the 26th International Epilepsy Congress held in Paris in August 2005. The new chapters are: Bangladesh, China, Emirates and Tanzania. There are now 96 national chapters making up the ILAE.

### **Chapters**

Albania Algeria Argentina Armenia Australia Austria Azerbaijan Bangladesh Belgium Brazil Bulgaria Burkina Faso Canada Chile China Colombia Congo Costa Rica Croatia Cuba Cyprus

**Czech Republic** Denmark **Dominican Republic** Ecuador Egypt Emirates Estonia Finland France Georgia Germany Greece Guatemala Honduras Hong Kong Hungary India Indonesia Iraq Ireland Israel



#### International League Against Epilepsy: A Primer

(continued from page 3)

and the Web site are overseen by the ILAE Information Officer and Web site Taskforce.

### **ILAE Finances**

ILAE finances are overseen by the Honorary Treasurer (M. Brodie), with the assistance of the Finance Office, who reports to the Executive Committee on financial matters. The income is derived from the dues of national chapters, sponsorship, income from *Epilepsia*, income from conferences, and investment income. In the current fiscal year, ILAE budgeted annual income is \$2,124,040, and budgeted annual expenses are \$1,563,790, and assets \$9,346,034. Membership of the Executive Committee, regional bodies, commissions and taskforces is honorary and members are not paid for this work. The editorship of *Epilepsia* and of *Epigraph* is also unpaid. Staff in the two administrative offices and the IDM office are salaried. 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.

Simon Shorvon ILAE Information Officer

### ILAE Executive Committee Meets Brussels, March 17-19, 2006



## ILAE Commissions and Taskforces

LAE is carried out through its Commissions' and 'Taskforces'. The individual Commissions and

Taskforces are nominated by the ILAE President at the beginning of each 4-year term. Each is given a schedule of work for the 4-year term and the Commissions and Taskforces meet regularly during this term. Each consists of a Chairman and members. chosen from colleagues around the world: and as is the case for all ILAE appointments, these posts are unpaid. Each Commission/Taskforce has a programme of action and is responsible to the ILAE Executive for the prosecution of this programme. A budget is allocated by the Executive to cover the expenses of the group, and each group provides an annual report of its progress. A final report is complied at the end of the 4-year period and most are posted on the ILAE website or published in Epilepsia. The Commissions and Taskforces can also organise workshops and other meetings and publish other documents as required.

Topic-related Commissions/Taskforces are constituted to address specific issues relating to epilepsy care worldwide and are responsible for developing ILAE policy and guidelines in various broad areas of activity. An example is the *Taskforce on* 

Classification and Terminology which is responsible for updating the ILAE Classifications of Seizures and Epileptic Syndromes, classification schemes which have had a profound influence on academic and clinical work in all countries over the past two decades. The Taskforce was divided into four working groups (Descriptive Terminology for Ictal Events; Seizures; Syndromes and Diseases; and Impairment) and has consulted widely amongst ILAE members worldwide. The report is now in press in *Epilepsia* and will no doubt be of major important to all future epilepsy work. The Commission on Neurobiology is another example of a Commission whose work is largely conducted by the organisation of scientific workshop, and which for instance conducted in the last term the biannual WONOEP (Workshop on Neurobiology of the Epilepsies; with supplements published in *Epilepsia*), a Symposium on Experimental Models of Infantile Epilepsies (with a book published resulting from the workshop), pre-congress courses in three regional ILAE congress (Latin American, Europe, Asia and Oceania).

The regional commissions are responsible for organising the regional conferences, regional publications and for developing regional policy in regard to epilepsy care. An example is the European Commission. In the last term this commission was the most active of all the regional Commissions. It held two major regional conferences, which attracted over 3000 participants each, annual international courses, an epilepsy summer school, a landmark conference in Russia. established a Working Group on Development of Quality of Care, contributed to the establishment of a Europe-wide pregnancy register to assess the comparative teratogenic risks of prenatal exposure to antiepileptic drugs, published several influential position papers, awarded European Bursaries for young persons to attend conferences and constituted a biannual European Epileptology Prize. The Commission has had an important influence on public policy in regard to epilepsy in Western European countries and has begun to focus its activities on assisting colleagues in Eastern Europe.

The Commissions and Taskforces of the current Presidency are in the process of appointment, and the following are those currently established by ILAE President Peter Wolf:

Regional Commissions:

• European Region (Chair - M. Baulac)

- Asian and Oceanian Region (Chair -C. Tan)
- North American Region (Chair J. Noebels)
- Eastern Mediterranean Region (Chair -B. Yaqub)
- South American Region (Chair -J. Moctezuma)

#### Taskforces:

- Faculty of Five hundred (Chair -E. Perucca)
- Investment policies (Chair P. Wolf)
- Web site and information (Chair -S. Shorvon)

#### Commissions:

- Classification and Terminology (Chair -A. Berg)
- Neurobiology (Chair A. Vezzani)
- Pediatrics (Chair tba)
- Therapeutic strategies (Chairs -J. French, G. Mathern)
- Neuropsychiatry (Chair -E.S. Krishnamoorthy)
- Epidemiology (Chair tbc)
- Genetics (Chair tbc)
- Epilepsy Care (Chairs G.Avanzini, P. Lee)
- Education (Chair E.M. Yacubian)
- Diagnostic Methods (Chair tbd)

### 2005-2009 ILAE Executive Committee



President Peter Wolf



Secretary-General Solomon Moshe



Treasurer Martin Brodie



Past President Guiliano Avanzini



1st Vice President Emilio Perucca



2nd Vice President Fred Andermann



Epilepsia Editor-in-Chief Phil Schwartzkroin



Information Officer/ Epilepsia Editor-in-Chief Simon Shorvon



IBE President Susanne Lund

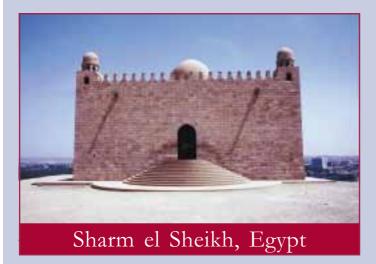


IBE Secretary-General Eric Hargis



IBE Treasurer Mike Glynn

### 2006 ILAE Regional Congresses



### 1st MEDITERRANEAN EPILEPSY CONGRESS

10 - 14 May 2006 1st East Mediterranean Epilepsy Congress Sharm el Sheikh, Egypt www.epilepsharm2006.com

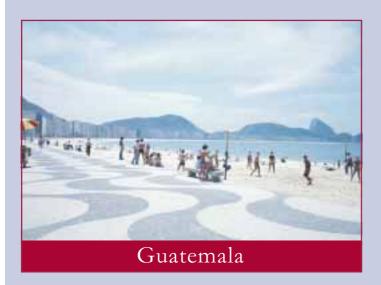
The scientific programme will include a pre-congress one-day course on seizure semiology and an interactive post congress workshop on EEG in addition to didactic lectures, platform sessions and satellite symposia on the other 3 days of the conference.





2 - 6 July 2006 7th European Congress on Epileptology Helsinki, Finland www.epilepsyhelsinki2006.org

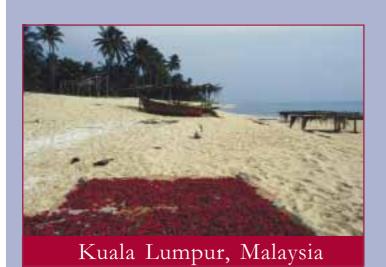
The Scientific structure of the programme will comprise four main topics, which have been carefully selected by the Committee to ensure a basic balance is achieved in the overall programme for the congress. The Main Topics which will provide a guideline theme for the entire meeting are 'Epileptogenesis, seizures and epilepsy', 'New concepts in pharmacotherapy', 'Brain maturation in epilepsy evolution' and 'Brain imaging from molecules to networks'.





6 - 9 September 2006 4th Latin American Epilepsy Congress Guatemala www.epilepsyguatemala2006.org

A stimulating and progressive programme constructed around the three key themes of Causes and Co-morbidity, How to Treat Difficult Epilepsies and Epilepsy and Society will challenge and inform all delegates who travel to Guatemala 2006.





16 - 19 November 2006 6th Asian & Oceanian Epilepsy Congress Kuala Lumpur, Malaysia www.epilepsykualalumpur2006.org

1 - 5 December 2006

Sessions include: Bridging between Laboratory and Clinical Epileptology, Genotype and Phenotype in Epilepsy, Imaging of EEG Spikes with MRI, Febrile Seizure and Epilepsy, Choice of Antiepileptic Drugs, New and Old Antiepileptic Drugs, Precipitating Factors and Types of Epilepsy, Psychogenic Non-epileptic Seizures



San Diego, California USA www.aesnet.org The 1st North American Regional Epilepsy Congress is the premiere conference for epilepsy and other seizure disorders. The Annual Meeting is an international forum for the exchange of current findings in epilepsy research. Information is communicated and disseminated through symposia,

lectures, scientific exhibitions, poster and platform presentations.

1st North American Regional Epilepsy Congress





The seven main topics in the scientific programme were selected by the Joint Executive Committees of ILAE and IBE, based on recommendations received from all ILAE and IBE chapters around the world. The Scientific Committees will focus on the following topics:

Issues in Developing Countries, Treatment of Epilepsy, Neuropsychological and Psychiatric Aspects, Men and Women with Epilepsy Throughout Life, Stigma and Quality of Life, Epileptogenesis in Relation to Genetic Predisposition in Abnormal Brains and Epidemiology and Prognosis.

### ILAE Launches Its Newsletter in a New Online Format

By Simon Shorvon, Editor of Epigraph and ILAE Information Officer

*pigraph,* the newsletter of the International League Against Epilepsy, was launched in 1994. It was a novel concept for the League, and for the first time in the League's history, Epiaraph provided a conduit for the transmission of ILAE information from the ILAE centre to its chapter members around the world. It struck a chord and in the past 10 years has continued with 2-3 editions a year and has retained throughout this period the same format, design, distribution method and the same editorial approach. Time, though, moves on, and in the past decade the rapid rise of online communication has rendered paper newsletters somewhat redundant. Furthermore, in the past four years, the ILAE Web site (www.ilae.org) has been developed to the extent that it has become the primary source of information about the ILAE. Epigraph had, in the view of some, become rather tired in format and content, and certainly its distribution lists had become progressively out of date.

At a meeting of the ILAE Web site Taskforce in October, therefore, the relative



roles of *Epigraph* and of www.ilae.org were debated and a number of decisions were made. It was decided to retain *Epigraph*, as it was felt that ILAE continued to need a mechanism to communicate directly with its members and *Epigraph* meets this need. However, we also recognized that the mailing of a print edition was wasteful of expense and materials — and that a far more efficient method would be via email. A decision was therefore made to convert Epigraph to become an essentially on-line newsletter, with its format changed accordingly and also to link *Epigraph* to the Web site far more closely.

The publishing plan is as follows. *Epigraph* will now come out in three online issues each year (winter, summer and autumn), with a single additional print edition published in the spring for inclusion in conference bags of the ILAE regional and international conferences. The three online issues will be emailed to members at their individual addresses, thereby cutting postal and production costs and the vagaries of the postal systems.

What you see on your email is largely an annotated index with links to articles and information on the ILAE Web site. The small size of the email will allow rapid opening and the reader can choose quickly what to read. Simply clicking on the links will lead to the relevant page on the Web site.

*Epigraph* (via its Web site links) will contain, as before, ILAE news, articles and information about ILAE activities and conferences, and links to its publications and administration. A new regular feature — Episcope, A Historical Note, will be included in each online edition. Occasional longer feature articles on topics related to epilepsy will be included.

As before, readers are welcome to submit articles at any time for consideration for publication in *Epigraph*, and we hope that these changes will enhance communication from ILAE for the benefit of all its members.

## Episcope, A Historical Note

Episcope, A Historical Note, is a new feature which will appear in each issue of *Epigraph* online. Each article will feature a paper of historical interest published in *Epilepsia* since its inception in 1909. The Episcope feature aims to provide a brief context to the article and its author and will be linked (by a simple click of a mouse)

to the full text of the paper which is freely accessible online. In this way, we hope to encourage readers to read the original papers, and to learn more about the contribution of ILAE to epilepsy.

### Chapter Template

ant to keep your members and the rest of the ILAE membership up to date with what your chapter is doing? Sign up for your free chapter Web page template on the ILAE Web site. Each template is linked with the respective chapter information page

and does not require any knowledge of Web design or editing. Simply update text and links and your chapter has its very own Web page.

To sign up for your own chapter Web page, email ndevolder@ilae-epilepsy.org



### The ILAE Web Site - www.ILAE.org

n the past few years, ILAE has developed a Web site. This has grown steadily and now has a key role in documenting and communicating ILAE activities. The Web site has been constructed in-house in the ILAE Hartford Office under the supervision of Christer Osterling and guided by the Web site Taskforce. 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 pages are currently in the process of development, and other sections in the planning stage. Currently, the following sections comprise the site:

### Home Page

The home page has been designed to show highlights and topical features and includes links to various other ILAE activities (Global campaign, conferences, EIC, *Epilepsia*, etc). Details of the recent election have also been posted.

### About the ILAE

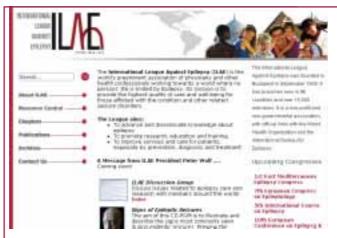
This area contains documentary information about the central ILAE structures and personnel.

- ILAE executive committee
- ILAE commissions and taskforces
- ILAE constitution and bylaws
- ILAE strategic plan
- Historical details.

### ILAE Resource Central

This area contains information about epilepsy. Among the entries are:

- Discussion group this is a new initiative launched in February 2006 and is described further on page 9.
- 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. One of the videos is available for online ordering as a trial run.



- Epilepsy Brochures. Ten brochures about epilepsy have been copied and put on line, 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.
- An International AED Database, compiled by Bob Fisher, is posted which 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.
- The proposals of the ILAE taskforce on classification and terminology.
- Details of future ILAE congresses and meetings with links to relevant Web

sites and in some cases on-line registration.

- Global campaign section presents details of the ILAE/WHO/IBE global campaign and links to the WHO Web site.
- ILAE reports section which contains copies of various current ILAE reports.
- ILAE annual report section contains the current annual report.
- 'Hot topics' section has been inaugurated and commissions for new articles are in place. This section aims to provide a short authoritative summary of clinical topics with links to recent *Epilepsia* papers.
- Links section has been inaugurated and provides links (via a click on the mouse) to other professional organizations.
- Selected scientific articles. This section contains a searchable selection (compiled by the Information Officer) of important papers on epilepsy

published each month (about 10 articles each month).

#### **Chapter Section**

This area contains information about ILAE chapters worldwide.

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

### **Publications Section**

This area contains information about ILAE publications

- The current editions of Epigraph.
- Information about *Epilepsia* and links to the journal Web site.
- A subscription area for discounted subscriptions for ILAE members for *Epilepsia* and four other epilepsy journals.
- ILAE Annual Report.

### **Archive Section**

This area contains archived copies of recent ILAE documents

- Non-current copies of *Epigraph* (from 1999).
- Annual reports of 2000 and 2002.
- The 'Awards section' includes details of ILAE awards and the recipients, since 1999, of the following awards: ambassador, lifetime achievement, Michael prize, social achievement, young investigators award.

### **Contact Details**

This section contains details of the Brussels and Hartford offices and personnel.

The Web 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.

### ILAE Adds Online Discussion Group To Site

By Andrew N. Wilner, MD, FAAN, FACP

fter more than a year of research and planning by the Web site taskforce, the ILAE launched an on-line discussion group for the exclusive use of its members in February 2006. This professional forum will be

available at no cost. Easy to use, the discussion group is for ILAE members to exchange views and comments and to post queries on any epilepsy clinical, research or related topic.

In 1994, the potential benefits of the internet to the practice of medicine were starkly highlighted by the case of Zhu Ling, a 21 year old chemistry student at Peking University in mainland China who became sick with a mysterious illness (1). She developed abdominal pain and her hair fell out, but she then recovered after treatment with traditional Chinese medicines. Three months later she deteriorated, developed facial paralysis and ultimately fell into a coma. Her physicians could not arrive at a diagnosis. Cai Quanging, a friend of Zhu Ling's, sent emails to doctors around the world describing her condition with a desperate plea for help. More than 2,000 responses came in from 18 countries, a number of which suggested the rare condition of thallium poisoning. As a chemistry student, Zhu Ling may have had access to thallium. Laboratory testing confirmed the diagnosis and treatment was initiated. The case of Zhu Ling demonstrated for the first time to millions of people the amazing role the internet could play in the practice of medicine. Anyone with a computer and internet access could now obtain a 'consultation' from physicians around the world.

Since Zhu Ling, more and more medical care depends upon internet communication. Lab results, xray images, and even EEG data can be relayed by the internet. Email communication is relied upon heavily by researchers and academicians and has begun to penetrate physicians' clinical practices as well. Many doctors have found that patient communication by email is more focused and efficient than telephone calls and has the advantage of creating a paper trail to document the interchange.

To further harness the advantages of the internet for its members, the ILAE Web



Andrew N. Wilner

'chats' allow one or more people to communicate back and forth in real time. Chats can even be performed with video However, 'chats' have limited application to an international group like ILAE

site taskforce examined the

pros and cons of different

types of internet-based

communication. Online

because of the difference in time zones of its members and the difficult logistics of having everyone

participate at the same time. Another type of internet communication tool is a 'Weblog' or 'blog' where daily entries are posted, usually by one person or a noncommercial organization. Blogs may

contain links to other Web sites and focus on news and other subjects, and may also resemble

format of a 'discussion 'forum', 'bulletin board', email and their responses are posted sequentially. Discussion groups have become very popular for

many topics. Members may be notified of updates to the discussion by an email from the group administrator and can check the discussion's progress by logging on to a designated Web site. Discussion groups may or may not be moderated for content and behavior.

The ILAE has members in nearly 100 countries crossing many time zones. This internet-based discussion group, available 24 hours a day and seven days a week, will provide an easy mechanism to facilitate communication between members on topics ranging from clinical research to patient care. Conversations between members that begin at the annual International Epilepsy Congress and regional meetings can be easily extended

throughout the year via this discussion forum.

In order to ensure the professional nature of the site, proper rules of decorum will be enforced and the site will be moderated by an epileptologist (Andrew Wilner, MD). This service has been expressly designed so that those with basic, 'dial-up' email access can have complete and easy entrée to the discussions. Instructions for the use of the site can be found on the ILAE home page (www.ILAE.org).

a later date. Topics initiated thus far include Epilepsy and Sleep, Posttraumatic Epilepsy, Vagus Nerve Stimulator, Distance Education Programme of EUREPA, Febrile Seizures in Adults, and Methsuximide. The vagus nerve stimulator discussion has been the most active, with 10 replies so far. The forum is an ideal venue for discussions regarding ILAE regional, national, and international congresses, clinical care conundrums, the development of a new ILAE epilepsy classification scheme, and other topics of interest to ILAE members.



To use the ILAE discussion group for the first time, members must register on the ILAE home page (www.ILAE.org) Registration is simple and allows identification of each member by name and region. After creating a username and password, members may contribute messages to ongoing topics of discussion or create their own topic (Figure 1). When members 'subscribe' to a particular topic, they will be notified by email of a response. A link will be provided in the email to bring them back to the discussion on the ILAE Web site. Members can also log-on to the ILAE Web site at their convenience to review postings by other members. Discussions are archived and may be searched by topic at

The ILAE Web site taskforce hopes that the discussion group will provide an enjoyable experience for ILAE members and enhance the care of patients with epilepsy everywhere. The discussion group provides another link for ILAE members to share their questions, answers, and experiences with their colleagues. Feedback from those who try the site is welcomed. Please direct any questions to Christer Osterling at costerling@ilaeepilepsy.org or Andrew Wilner, MD (andrew.wilner.md@aya.yale.edu).

#### **References:**

1. International Electronic Link Solves Medical Puzzle. JAMA 1995;274(22):1750.

personal online journals. After much deliberation, the Web site taskforce selected the

> group', also known as a or 'list-serve', where members initiate or respond to topics by

## Schwartzkroin and Shorvon Appointed as Epilepsia Editors

By Phil Schwartzkroin, Joint Editor-in-Chief, Epilepsia

On 31 December 2005, Robert S. Fisher stepped down as Editor-in-Chief of *Epilepsia*. Dr. Fisher has helped guide *Epilepsia* to a prominent position as one of the elite neurological journals, and the academic epilepsy community owes him much gratitude for his erudite and effective leadership. As the official journal of ILAE, *Epilepsia* reflects the extraordinary breadth of the epilepsy research community, as well as its geographical diversity. These are features that we, the new editors, hope to maintain and further expand.

*Epilepsia*'s priority will remain the publication of high quality science that contributes to our knowledge about, and treatment of, epilepsy. As new editors, Simon Shorvon and I invite submissions from all parts of the world, covering all aspects of epilepsy investigation. We are committed to the broad dissemination of epilepsy information and provocative discussion. These goals will be met via high quality peer review, rapid turnaround time, and expedited processing of articles of particular import and interest. The

journal will be *Schwartzkroin* dedicated, first

and foremost, to the publication of original research papers in clinical and basic science aspects of epilepsy. In addition, *Epilepsia* will feature reviews on topical issues, as well as editorial commentary that stimulates discussion and debate. As the journal of ILAE, *Epilepsia* will feature general interest reports from ILAE Commissions. Reports from epilepsy-relevant conferences and workshops will also contribute to the educational mission of the journal. As in the past, the *Epilepsia* supplements will provide "added value" to the journal subscription.



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apparent to Simon Shorvon and me as incoming editors that the general landscape of academic publishing is changing rapidly. The development of internet technology has provoked vigorous discussion about open-access publishing and led to many issues — scientific, political, and financial — regarding traditional methods of print publication. *Epilepsia* will, inevitably, change in response to these pressures. It is our job as editors to make those changes proactively, with thoughtful deliberation and input from the journal's readership. Change and innovation will be carried out within the context of our mission — to maintain the highest scientific standards for the journal, and to make epilepsy knowledge widely available to the international epilepsy community.

Epilepsia plays a special role in the epilepsy academic community. Our goal is to maintain Epilepsia as the premier journal for clinical epilepsy papers, as well as for basic science research in particular areas of translational neuroscience. Epilepsia should be the first choice journal — for epilepsy specialists as well as for biomedical researchers in related disciplines — as a source of leading-edge information in the field. Through the efforts of the professionals that use the journal, Epilepsia can become an active player in the advancement of epilepsy research and treatment. We are grateful for the opportunity to lead these efforts, and look forward to broad participation from you, our colleagues.

# Discounted Subcriptions for ILAE Members

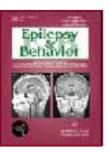
he International League Against Epilepsy publishes its own international scientific journal *Epilepsia.* This is its primary vehicle for the dissemination of scientific and clinical information about epilepsy. It was launched in 1909 and is now the major epilepsy specialist journal and has the highest impact factor among epilepsy journals. Over the years, many leading research papers and reviews have been published in its pages, and it is an essential read for all clinicians and scientists interested in epilepsy. Online access is also available to the archive of back issues. The archive is currently incomplete, but within the year it is hoped to archive all copies back to 1909. This complete library is a vital resource, covering scientific papers on many aspects of epilepsy.

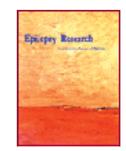
ILAE is pleased to offer reduced subscriptions to members and we urge all ILAE members to subscribe — these rates offer tremendous value.

In addition, ILAE also offers discounted subscriptions to its members for

Epileptic Disorders

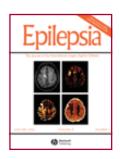






the other specialist epilepsy journals shown below.

All these publications are available as print and/or online subscriptions, and subscriptions can be purchased through the International League Against Epilepsy's secure online order form. Visit http://www.ilae.org/visitors/publications/ index.cfm for more information.





The Global Campaign has published an atlas of epilepsy care in the world, covering 97% of the world's population.

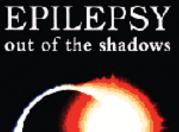
## Out of the Shadows — the Global Campaign Against Epilepsy

he Global Campaign Against Epilepsy is a joint initiative of ILAE, the World Health Organization (WHO), and the International Bureau Against Epilepsy (IBE). Its mission is to bring epilepsy "out of the shadows" by improving diagnosis, treatment, prevention and social acceptability of the disorder world-wide. It aims to do this by:

- Increasing public and professional awareness of epilepsy as a universal treatable brain disorder
- Raising epilepsy to a new plane of acceptability in the public domain
- Promoting public and professional education about epilepsy
- Identifying the needs of people with epilepsy on a national and regional basis

 Encouraging governments and departments of health to address the needs of people with epilepsy, including awareness, education, diagnosis, treatment, care, services and prevention.

The first phase of the Global Campaign Against Epilepsy was launched in June 1997 and 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 initiated this year and concentrates on special projects and on assisting healthcare providers on epilepsy matters. The campaign is being led by the immediate ILAE past president Guiliano Avanzini for the ILAE, and Phil Lee for the IBE. Further details are available on the ILAE Web site.







is edited by Professor Simon Shorvon with the assistance of Christer Osterling in the ILAE Hartford office. The print edition is kindly sponsored by an unrestricted educational grant from Pfizer.

All communications should be directed to Christer Osterling at epigraph@ilae-epilepsy.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