

Information Officer Report

Welcome to this, the Spring 2006 issue of *Epilepsia*. 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 *Epilepsia*. The online issues are sent by email to all ILAE members and have a newsletter function and format — and on page 10 there is an article which provides more details on this new ILAE initiative. In contrast, this print edition is intended primarily to 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 progressively grown 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 issue. I have included 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 website, the online newsletter *Epilepsia* and the ILAE's scientific journal *Epilepsia*. The most important new initiative of the ILAE is to promote epilepsy education — and Peter Wolf, ILAE

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President's Message

Greetings
As of the last evening of August 2005, a new team of ambassadors 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 elected as the new joint Editors-in-Chief of *Epilepsia* on the retirement of Bob Fisher in Dec 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 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.
- 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 1999, others apply to Asia/Oceania with their active regional academy ASEPA. EUREPA via a Francophone Section has reached out to the French-speaking countries in West and Central Africa, and a Lusophone Section is under development 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.

Continued on page 2

President's Message

(continued from page 1)

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 task forces 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 global 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 global 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 and may get the right to vote for an additional Vice President.

Global Campaign

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

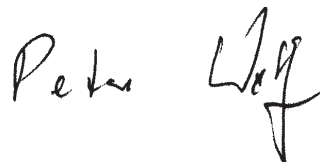
The old Commission on Asian and Oceanian Affairs is still conducting the business of the region as the new Commission can only be finalized after the elections of the additional Vice President from that region have been accomplished. Nonetheless, they have produced a report

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. 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.



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



THE INTERNATIONAL LEAGUE AGAINST EPILEPSY (ILAE) – a primer I.

The ILAE is an international non-profit 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 95 countries and over 15,000 members worldwide.

The mission of the ILAE is to work towards a world where no persons' 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 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 Moshe), 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 four 4 term. The President (S Lund), Secretary General (E Hargis) and Treasurer (M Glynn) of the sister organisation, the International Bureau Against Epilepsy (IBE), are ex-officio 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 Website. The constitution has sixteen articles, and the bylaws has 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.

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, but generally speaking membership is open to any doctor and health professional interested in epilepsy.

There are currently 95 CHECK chapters in the ILAE, which is the greatest number in its history. The largest is the American chapter with XXXX members, and the smallest is XXX with XXX members. The role of the national chapters is generally to establish and maintain good communication between persons active in the field of epilepsy, organise or sponsor national meetings, appoint commissions or individuals for specific problems, develop or apply other methods for the furtherance of the objectives of the ILAE.

REGIONAL BODIES

ILAE is also divided into 6 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 3 national chapters CHECK FIGURES). 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 Baulac), Asian and Oceanian Commission (Chair – SH Lim), North American Commission (Chair – J Noebels), Latin American Commission (Chair – J Moxezuma), Eastern Mediterranean Commission (Chair – B Yaqub).

ILAE COMMISSIONS AND TASKFORCES

In every 4 year term, the President and the Executive Committee appoint Commissions and Taskforces, to carry out

work for the ILAE. These bodies involve individual members trans-nationally. Currently, the following topic-related commissions and taskforces are constituted: Constitutional Taskforce (Chair G Avanzini), Classification TaskForce (Chair – A Berg), Website Taskforce (Chair – S Shorvon), Neurobiology commission (Chair – A Vezzani), Pediatrics commission (Chair – H Cross), Therapeutics Strategy commission (Chair tbc), Psychobiology commission (Chair – P Genton), Epidemiology commission (tbc), Genetics commission (tbc), **Commission on the Development of Epilepsy Care (Chair – G Avanzini)**.

ADMINISTRATIVE OFFICES

The ILAE has two administrative offices. The Financial office is in Hartford and the ILAE HQ is in Brussels. The Hartford officer oversees the administration and is lead by Mr Peter Berry. There are XX 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 (Website Project manager), Nele Delvolder (Membership Services).

ILAE CONFERENCES AND THE OFFICE OF THE IDM

ILAE holds a global scientific conference once every 2 years (Epilepsy International Congress). Each region holds a regional scientific conference every 2 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 organised by its own conference organiser (Richard 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 launched 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 is 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.

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 also an editorial board and associate editors. EPILEPSIA was started in 1909, and currently is published on a monthly basis. 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 WEBSITE AND EPIGRAPH

Ten years ago, the ILAE launched its own newsletter EPIGRAPH, to be sent individually to all individual members. This was initially sent out 2-3 times a year, but from 2006 4 issues are year will be published – 3 online and one in a print edition. 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. 4 years ago, ILAE also launched a website (www.epilepsy.org). [OR PRIMARY NAME]. This has grown in size and complexity and in 2005 there were 249,911 visits. EPIGRAPH and the Website are overseen by the ILAE Information Officer and Website 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, expenses are \$1,023,282, and assets \$9,346,034. Membership of the Executive Committee, regional bodies, commissions and taskforces is honorary and members are unpaid for this work.

2005-2009 ILAE Executive Committee



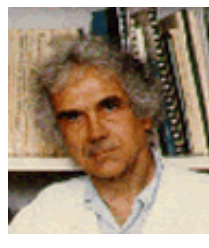
*President
Peter Wolf*



*Secretary-General
Solomon Moshe*



*Treasurer
Martin Brodie*



*Past President
Giuliano 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*

Schwartzkroin and Shorvon Appointed as Epilepsia Editors

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

On 31st 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 turn-

around time, and expedited processing of articles of particular import and interest. The Journal will be 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.



Schwartzkroin



Shorvon

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

While the position of *Epilepsia* seems tranquil and secure, it is increasingly apparent 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.

ILAE Launches Its Newsletter in a New Online Format

By Simon Shorvon, Editor of Epigraph and ILAE Information Officer

Epigraph – 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 – Epigraph 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 Website (www.ilae-epilepsy.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 Website Task Force in October, therefore, the relative roles of Epigraph and of www.ilae-epilepsy.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 website 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 out 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 website. 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 website.

Epigraph (via its Website 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 - Episcopes, 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.

Episcopes, A Historical Note

Episcopes, 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 Episcopes 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.

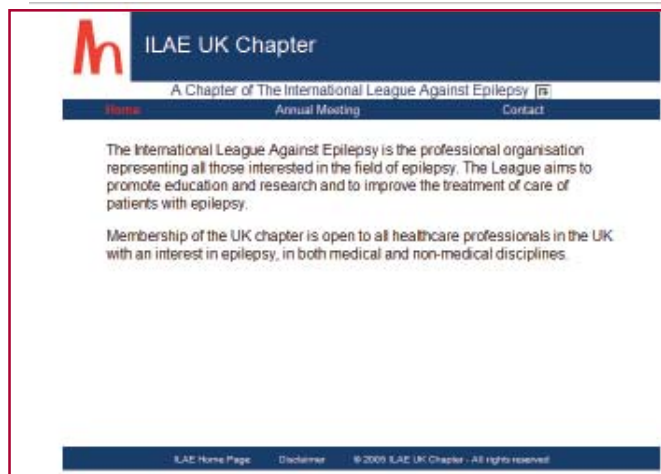
Chapter Template

Want 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 up 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 it's very own Web page.

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





Singapore 2007

27th INTERNATIONAL EPILEPSY CONGRESS 8th - 12th July



**THE ILAE WEBSITE -
www.ILAE.org**

In the past few years, ILAE has developed a website. This has grown steadily and now has a key role in documenting and communicating ILAE activities. The website has been constructed in-house in the ILAE Hartford Office under the supervision of Christer Osterling and guided by the Website TaskForce. The website has three main roles:

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

The site continues to develop. There are new pages which are currently in the process of development, and other section in the planning stage. Currently, the site comprises the following sections:

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.

- Information about the ILAE executive committee
- Information about ILAE commissions and task forces
- ILAE constitution and bylaws
- ILAE strategic plan
- Historical details.

ILAE Resource Central

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

- Discussion group – this is a new initiative launched in February 2006 and is described further on page XX of this issue of EPIGRAPH
- ILAE Worldwide Resource Directory. This is now complete. It is a searchable database of the EIC collection of 1500 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 on-line ordering as a trial run- Epilepsy brochures.

A section of 10 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, 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 which country certain medications can be found.

• The proposals of the ILAE task force on classification and terminology.

• Details of future ILAE congresses and meetings with links to relevant websites and in some cases with on-line registration.

• Global campaign section presents details of the ILAE/WHO/IBE global campaign, and links to the WHO website.

• 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 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 (list is in process of compilation).

• Selected scientific articles. This section contains a searchable selection (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 chapter and their officers and council members. There are links to the chapter website (where available) and email contact details.

• The annual reports of individual chapter are also posted where these are 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 website.

• 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

• Details of the Brussels and Hartford Offices and personnel.

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 the back page, and those readers who are non-members are strongly encouraged to join. Membership is through national chapters, and details of how to join are provided on the back page.

Simon Shorvon
Editor, *Epigraph*

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 \$10 per year per member, 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 and editor of EPIGRAPH.



After more than a year of research and planning by the website task force,

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 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 Quanqing, 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 website task force examined the pros and cons of different types of internet-based communication. Online '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 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 websites and focus on news and other subjects, and may also resemble personal online journals.

After much deliberation, the website task force selected the format of a 'discussion group', also known as a 'forum', 'bulletin board', or 'list-serve', where members initiate or respond to topics by 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 website. 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 7 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).

Nerve Stimulator, Distance Education Programme of Europe, 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.

The ILAE website task force hopes that the discussion group will provide an

The screenshot shows the ILAE website interface. At the top is the ILAE logo (International League Against Epilepsy) and a world map. Below the logo is a navigation bar with links for Home, General Epilepsy Discussion, and Vagus Nerve Stimulator. The main content area displays a forum thread titled "Thread: Vagus Nerve Stimulator". The thread details include the creation date (01/27/06 01:55 PM), the number of replies (10), and a list of posts from various users including Tony Rogers (USA), Emilio Perucca (ITALY), Andrew Wilner (USA), and Emilio Perucca (ITALY). Each post entry shows the user's name, location, the subject of the post, the date and time, and a brief snippet of the text. Links for "Link", "Top", and "Bottom" are provided for each post.

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 website. Members can also log-on to the ILAE website at their convenience to review postings by other members. Discussions are archived and may be searched by topic at a later date. Topics initiated thus far include Epilepsy and Sleep, Posttraumatic Epilepsy, Vagus

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 costerline@ilae-epilepsy.org or Andrew Wilner, MD (Andrew.Wilner.MD@aya.yale.edu).

References:

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

New Chapters

The International League Against Epilepsy (ILAE) approved four new member chapters at the 26th International Epilepsy Congress this past August in Paris, France.

The four new chapters are
XXXXXXXXXXXXXXXXXXXXXXXXXXXX



List of Chapters

ILAE Offers Signs of Epileptic Seizures CD For Sale on Site

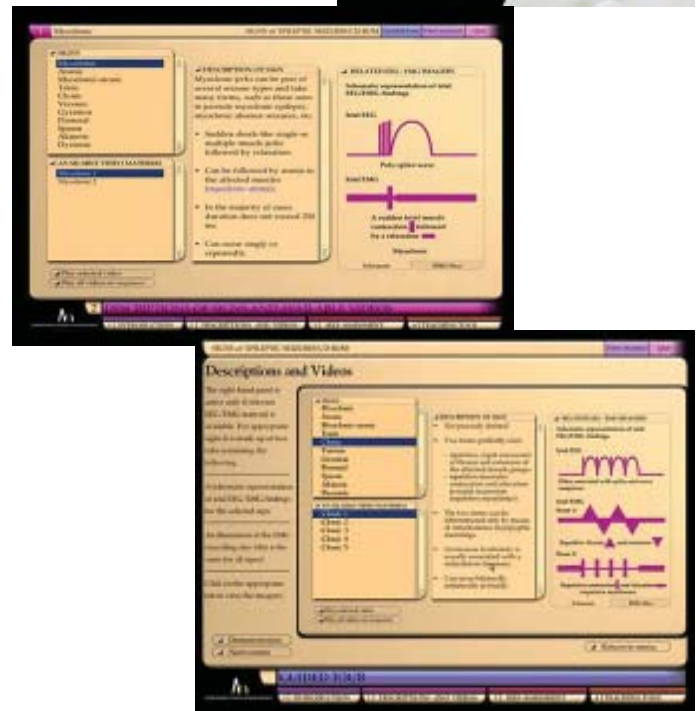
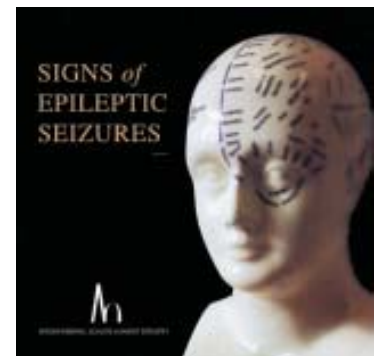
The aim of this CD-ROM is to illustrate and describe the signs most commonly seen during epileptic seizures. It is designed for use both as a teaching tool and for self-education. Purely subjective signs cannot be demonstrated by means of video and are therefore not included. From the clinical point of view, epilepsy is an organically established tendency to recurrent seizures. The seizure itself plays a central role in the diagnosis and treatment of epilepsy. Therefore it is important to recognize, identify and be able to adequately describe the various clinical signs that may comprise a seizure, in order to ensure a correct classification as a basis for therapeutic strategies.

A seizure is a paroxysmal disturbance of central nervous system function and is associated with excessive neuronal discharge that is synchronous and self-limited. This neuronal dysfunction can interfere with normal behavior and lead to alterations of motor, sensory and psychological function. During the course of an epileptic seizure or in the immediate post-ictal phase, a wide variety of signs may be observed that occur either sequentially or simultaneously. Thus the video clips in this CD-ROM often feature the same patient, and in some cases the same seizure, to illustrate different signs.

Some of the video clips are very short because single signs have been extracted from the whole seizure in order to avoid overlap with other signs that might cause confusion.

Normal practice is to give some background information on patients and their case histories to avoid presenting patients as mere objects of study. In this CD-ROM, however, clinical data might misleadingly suggest an association of the sign with a particular seizure type, as the same sign occurs during many different seizure types. Therefore no clinical details are given, and the EEG descriptions and other electromyographic data are presented only when appropriate.

The summaries of the selected signs are purely descriptive and are based on ictal video recordings. They should not be interpreted as definitions in the sense of an official terminology catalogue. Additional findings from ictal surface electromyograms (EMGs) have been included in the descriptions of motor phenomena because they offer the only means of distinguishing between motor events of a short duration that cannot be properly differentiated by clinical examination and thus require simultaneous EMG recording.



Discounted Subscriptions for ILAE Members

The 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 amongst epilepsy journals. Over the years, many leading

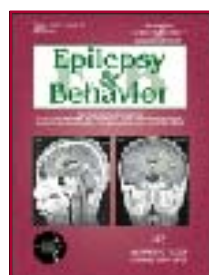
research papers and reviews have been published in its pages, and is an essential read for all clinicians and scientists interested in epilepsy. Online access is also available to the archive of back issues. The archive is currently incomplete, with issues back only to 1937, but within the year it is hoped to archive all copies back to 1909 when *Epilepsia* was founded. This

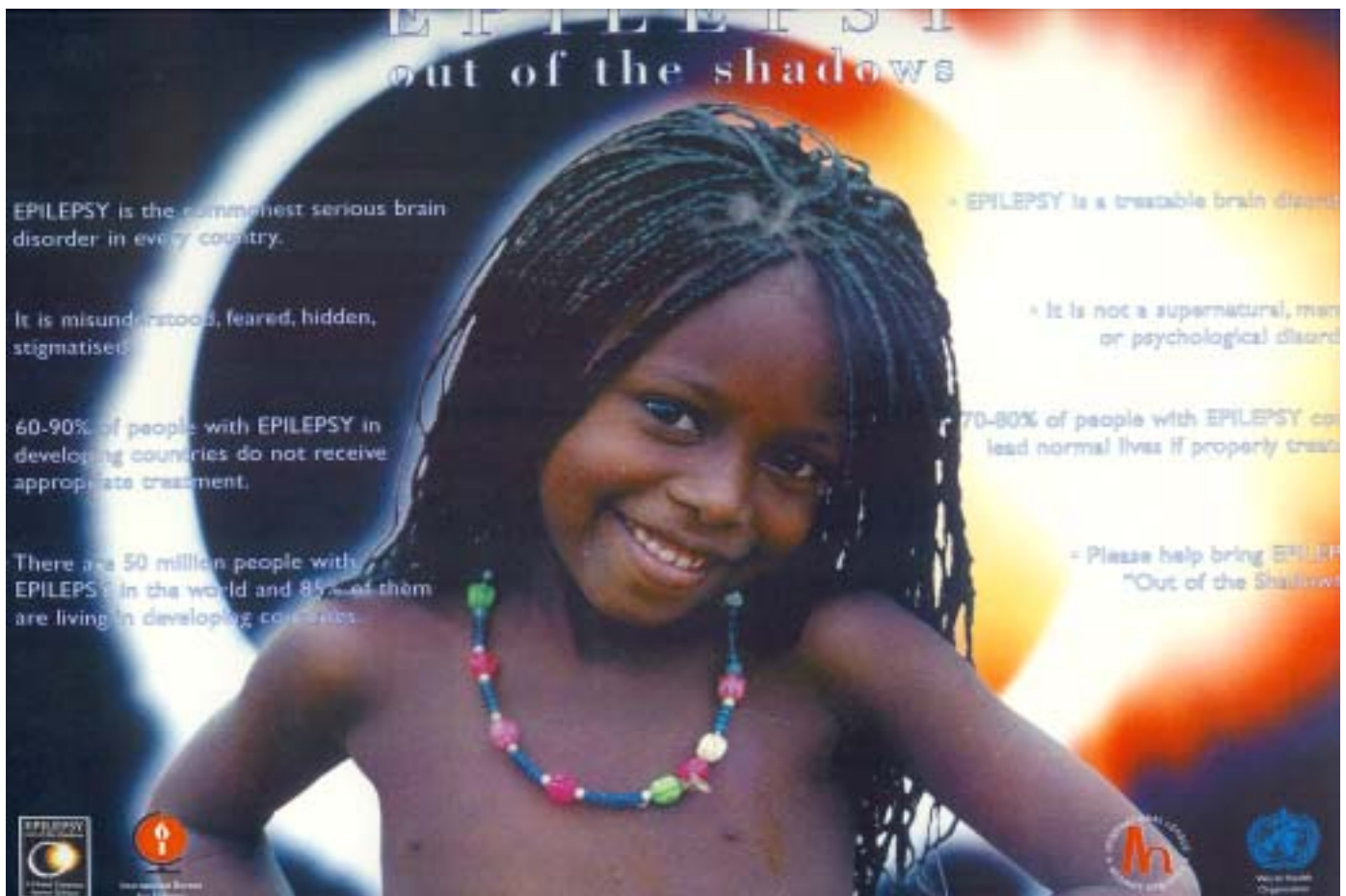
complete library is a vital resource, covering scientific papers in many aspects of epilepsy.

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 to 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





OUT OF THE SHADOWS – THE GLOBAL CAMPAIGN AGAINST EPILEPSY

The Global Campaign Against Epilepsy is a joint initiative of ILAE, the World Health Organization (WHO), and the International Bureau for 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 on 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 health-care 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 website



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