

EDITORIAL

This is the time for baton passing at ILAE! A fresh Executive Committee takes over the running of the League at the General Assembly during the Paris meeting. For me it is time to say goodbye as my term in office at ILAE is coming to an end. For the last six years I have been involved with Epigraph, initially as a co-editor with Simon Shorvon and over the last four years as the editor. In addition, for the last four years, I have had the honour of being an elected member of ILAE Executive Committee and on the management committee, serving as the Treasurer. Both of these posts were fulfilling experiences and I have really enjoyed serving and I hope I have made a positive contribution to ILAE.

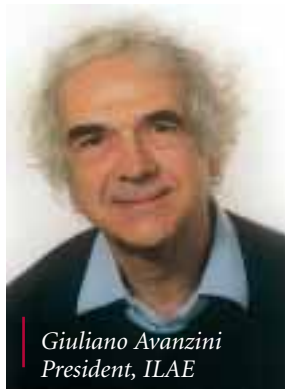
Epigraph has gone from strength to strength in these years and is highly valued by our members as a vehicle for imparting all that is new at ILAE. In these years at Epigraph, Juliet Solomon has immensely helped my work, running it on a day-to-day basis, chasing up our contributors and making sure it was delivered on time. I am very grateful for her help and support. Talking about support, I would also like to thank, Giuliano Avanzini, ILAE out-going president and Simon Shorvon, ILAE's Information Office for entrusting me with the running of Epigraph in their watch.



The financial situation of ILAE is solid and, indeed, over the lifetime of the retiring Executive Committee

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President's Message



Giuliano Avanzini
President, ILAE

Looking back over the four years since the present Executive Committee (EC) took over in Buenos Aires, I sometimes wonder how far we have managed to implement the actions I have highlighted in a long series of EPIGRAPH messages which have concerned our management system, interactions with our Chapters, our communication systems, our Congress and educational activities, and our production of diagnostic and therapeutic guidelines and recommendations.

Management

The completion of the Headquarters Office in Brussels has led to a management system of an Administrative Director coordinating the US, and Headquarters offices have become fully operational. Its services have become familiar to all ILAE officers (including Commission Chairs) and members, ILAE Chapters, and the other organisations with which we regularly work, such as the International Bureau for Epilepsy (IBE) and the World Health Organisation (WHO). Its effectiveness was demonstrated by the success of the election process, an unusually high percentage of voting Chapters and an unusually small number of invalid votes.

Above all, the new management system has significantly contributed towards improving interactions with the Chapters, thus giving them a stronger feeling of being directly involved in the life of the ILAE. This leads me to something I have repeatedly stressed in my previous messages as a crucial aspect of the actions of the EC.

ILAE Chapters

During our term, the number of ILAE Chapters increased from 76 to 95 (including the three provisionally accepted Chapters that will become full ILAE members after their acceptance by the General Assembly in Paris) This rapid development made it essential to ensure an effective two-way communication system with our membership. To this end, an increasingly important role is now being played by the Chapter Conventions started in 2002, and repeated during the International and Regional Epilepsy Congresses, which give Chapters the opportunity to meet, exchange their points of view, be updated about ILAE policy and actions, make suggestions concerning the future of the League, and discuss new services that the ILAE could offer.

As discussed during the Strategic Planning Meeting held in New Orleans on 4 December 2004, a number of the inputs and stimuli generated by the Chapter Conventions have been particularly important in orienting ILAE strategies and deserve to be reported here in some detail.

- Despite the continuing commitment of the ILAE and IBE, the number of people with epilepsy who are not appropriately treated is still unacceptably high, and our strategy should be to map the situation in different parts of the world/regions/countries, and to propose appropriate measures that can

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be taken by governments and other relevant organisations (the World Bank, the WHO, UNESCO, the EU, etc.). A primary role in this should be played by the Global Campaign Against Epilepsy (GCAE), organised in partnership with the International Bureau for Epilepsy (IBE) and the World Health Organisation (WHO).

- The present evolution towards the regionalisation of the ILAE should be pursued and reflected in virtually every point of the Strategic Plan, starting from the treatment gap. It should also have a clear impact on the ILAE organisation (e.g. administrative structure) and actions (e.g. GCAE).
- The ILAE's efforts to improve communications should be pursued considering new tools such as Congress-related videoconferences ("virtual Congresses") and tele-medicine.
- The importance of the ILAE's educational activities is widely acknowledged. The model provided by the European Epilepsy Academy (EUREPA) is generally appreciated, and it was

felt that we should also seek partnerships between the educational institutions of the developed and developing worlds. Moreover, innovative educational approaches (remote education) and mentorship/training programmes (including training the trainers and training the tutors) should be implemented.

- Interest has been expressed in strategies capable of promoting, facilitating and supporting international collaborative studies of genetics, epidemiology, etc., and stimulating research training programmes in the different parts of the world (particularly in developing countries). This is an issue about which I am particularly sensitive: I believe that it is very important to help developing countries to establish research projects that will enable them to confront their specific problems, and that this should be supported by ILAE resources and by proposing fellowship/grant programmes aimed at promoting epilepsy research to the relevant institutions (the World Bank, the

WHO, UNESCO, the EU, governments, etc.)

- Our present good relationships with the pharmaceutical industry should be pursued and developed with the aim of guiding industrial policies (and not vice versa).
- Our relationships with governments and NGOs, and our partnership with the IBE and WHO (i.e. GCAE), are of primary importance for the development of future ILAE strategies.

Communication systems

Communications with the individual members of ILAE Chapters have been a priority of the EC, which has taken particular care to promote our journal *Epilepsia*, our newsletter *Epigraph*, and the ILAE website.

Epilepsia continues to be the most authoritative journal in the field, and its impact factor continues to increase. This is due to the work of its Editor-in-Chief and the Editorial Board he has built up, as well as to the professional assistance of its publishers Blackwell. One of the results I would like to mention is the development of a special programme designed to make the journal accessible online to people living in economically disadvantaged countries. We were sorry to hear that Robert Fisher will not be available for a further mandate, and I thank him very much for his outstanding work on behalf of the ILAE.

The six-monthly *Epigraph* has now become familiar to all of the members of our Chapters, who can find a brief but complete summary of the most important news in an elegant and attractive format. The editor Ley Sander and his assistant Juliet Solomon deserve our gratitude for running the newsletter so effectively by silently doing an enormous amount of work in such a professional and creative manner.

The ILAE website has greatly developed under Simon Shorvon's

editorship and Joseph Wall's professional assistance. It currently provides a complete and continuously updated repertory of the ILAE's structures and activities. As the ILAE's Information Officer, Simon Shorvon is also responsible for the Epilepsy Information Center (EPI-info) at the Swiss Epilepsy Center in Zurich, the specific duties of which are to maintain a library of ILAE documents & videos, assist in providing data for updating the journal and book lists, provide e-mail responses to queries, and to maintain the ILAE's historical archives.

Congresses and Courses.

There is no need to stress here the importance of the International Epilepsy Congresses organised every two years in collaboration with the IBE, of which the forthcoming 26th Epilepsy Congress will certainly represent a further important milestone.

One interesting evolution of ILAE Congress activities has been the successful development of biennial Regional ILAE Congresses in the years in which there is no International Epilepsy Congress. This aspect of the progressive "regionalisation" of the ILAE organisation has been greatly aided by the productive initiatives of the Regional Commissions (developed on the basis of the WHO model).

The success of the ILAE Congresses once again demonstrates the appropriateness of the decision to create the office of the International Director of Meetings (IDM), and underlines the fact that the ILAE should continue in this way while taking into account the lessons learned from our first four years' experience. To this end, when the previous IDM contract expired, its advantages and limitations were carefully evaluated and, on the basis of the results, a new contract was drawn up by the ILAE and IBE, to be agreed with Richard Holmes, whose outstanding contribution is gratefully acknowledged.

EDITORIAL

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our reserves have trebled. Our international congresses and our official journal *Epilepsia* have been mainly responsible for this healthy situation. My role as treasurer was made easy by the diligence and dedication of Donna Cunard, our Finance Officer in Hartford, to whom I am very grateful. Peter Berry, in his role as Administrative Director, provided invaluable support and advice. I also enjoyed working with Mike Ziebka, our auditor and Art Herold, legal adviser.

This issue of *Epigraph* is a transitional one and, therefore, it chiefly covers the departure of old faces and the welcoming of new. Giuliano Avanzini's last presidential message is on pages 1-3. The Incoming President, Peter Wolf, has already written an introductory message in the last issue of *Epigraph*. From pages 3 onwards we introduce the new ILAE Executive Committee and Jerome Engel writes a short piece on the role of the Past President. Pages 6-8 are filled with news from around the globe in our Bulletin Board section.

Finally, I would like to thank Janssen, Novartis and Pfizer for their support of *Epigraph* over these years - we are most grateful to them.

We wish all luck to our new Executive Committee and hope their term in office will be successful.

Ley Sander Editor and ILAE Treasurer

Many other educational activities have taken place (inside and outside the Congresses) as a result of the work of the European Epilepsy Academy (EUREPA), which is now evolving into the ILAE educational branch. I would particularly like to mention the increasingly successful Residential Summer Courses held in Venice, each of which has involved the active participation of one or more ILAE Commissions depending on the topics covered.

Guidelines and Recommendations

It is impossible to mention here all the documents which the ILAE Commissions have made available to all our associated colleagues concerning recent advancements in work to improve epilepsy care. In this context, particularly important work has been carried out by the Task Force on Classification, which has reviewed the current classification of seizures and epilepsies taking into account the comments, suggestions and criticisms received from individuals or Commissions. The results of this major work in progress have been regularly published in *Epilepsia* and communicated at our Congresses, and are based on new concepts that advance our understanding of the pathophysiology and clinical aspects of Epilepsies.

Partnerships with the IBE, WHO and other NGOs

The importance of the partnerships with the IBE and WHO is clearly demonstrated by the exciting progress of the Global Campaign Against Epilepsy (GCAE). Readers are referred to the report prepared by Pete Engel, Hannecke de Boer and Leonid Prilipko, to whom I give my warm thanks on behalf of the EC.

As usual, I have run out of space before I could cover all of the points I had in mind. But I would like to stress at least one important action carried out by the ad hoc task force: the revised ILAE Constitution and By-laws

you have received in preparation for the ILAE General Assembly in Paris. The Chair of the Task Force, Natalio Fejerman, and all of its members deserve our gratitude for completing this major work on time.

But what I have said above should not lead to a wholly positive evaluation of our term in office because, despite our efforts, the ILAE mission of spreading the benefits of its actions to everyone suffering from epilepsy is still far from being accomplished: millions of people with epilepsy still do not receive appropriate treatment or are not treated at all. Furthermore, the last four years saw some unpleasant problems with some of our Chapters that were partly due to misunderstandings (for which I am ready to take my share of responsibility), but also partly due to internal conflicts that reflected an unexpectedly high degree of aggressiveness. We also received four slanderous and anonymous letters, the most contemptible and cowardly way of attacking anyone's credibility.

I hope that this will never happen again. I wish the ILAE and its incoming Executive Committee every success in running an organization that we are proud to be able to hand over: a lively association that has not only made some important steps forward over the last four years, but is also capable of fulfilling further ambitious tasks.

Giuliano Avanzini
President ILAE

OFFICERS' NEWS

Incoming/outgoing

MARTIN BRODIE

Treasurer Elect



For the past four years it has been my privilege to serve as Second Vice President on the executive committee of ILAE. Expecting a nominal role only, I was delighted to be invited by Giuliano Avanzini to chair the "Taskforce for Regional Commissions". It has long been my view that "regionalisation" is essential to the development of our global epilepsy agenda. This approach splits up an unwieldy 92 chapters (rising to 94 in Paris!) into smaller more manageable groups of like-minded people with similar problems and aspirations. Over the past four years, considerable progress has been made by the regional commissions in Europe, Asia and Oceania, Latin America and the Eastern Mediterranean area. The challenges of Africa largely remain to be tackled. North America remains the exception that proves the rule! I am particularly pleased with the template for the biannual regional congresses. The European meetings continue to grow in scientific stature and organisational sophistication. The congresses in Asia and Latin America are now starting to catch up. We held highly successful conferences in Vienna, Mexico City and Bangkok during 2004. In 2006, we hope to exceed their achievements in Helsinki, Guatemala City and Bali and, for the first time, we plan to hold an Eastern Mediterranean congress.

The positive experience of working within our epilepsy family has led me to offer my services to the League for a further term. Thanks to the support of friends in many chapters, I am now ready to take up the challenge of supervising the finances of the League within a strong new team led by Peter Wolf. Since we are in a relatively healthy financial position, I hope to be seen as a "spending" chancellor of the exchequer (within reason, of course, as I am, after all, a Scotsman!). A major focus of our agenda will be on education. The revolution in communication technology makes it possible to reach out to people equally in the developed and developing world. E-learning technology has provided us with a cost-effective way of spreading epileptology expertise across the planet. I'm looking forward very much to the challenges ahead and to meeting many more chapter members over the next four years!

Martin J Brodie

NATALIO FEJERMAN

Outgoing Secretary General



I started working as Secretary General of ILAE on June 15th, 2001 and soon realized that it was very difficult to keep updated on the chapters and their activities, and on the commissions of ILAE. Therefore, from the outset my main task was to improve communication with the chapters by first creating a complete and updated database. The creation of ILAE's Administrative Headquarters in Brussels was a great step forward toward a more effective and efficient organization.

A major achievement was the Chapters' convention, which followed the initial one we held in Madrid in 2002. Since then, we have had very fruitful meetings with the majority of chapters in the International Epilepsy Congress in Lisbon and in the Regional Congresses which took place in Vienna, Mexico and Bangkok. Although I was not able to attend, the Mediterranean meeting in Marrakesh was also a fruitful gathering of the chapters. All the delegates of the chapters participating were again very active and I am glad to say that the ideas brought to these gatherings are clearly improving the relations between all the chapters and ILAE's Executive Committee.

Regarding new chapters, we were able to increase to 92 the number of countries represented in ILAE. We received requests for applications from several new countries, and a completed form has already been sent in by China. As you will realize, the eventual incorporation of China as a Chapter of ILAE would allow us to include membership representation of the largest population of patients with Epilepsy in the world.

With the support of the Spanish speaking chapters of Spain and Latin America, I am trying hard to publish the *Epilepsia Digest* in Spanish with the intention that it should be freely distributed to all the members of the relevant regions.

As Chair of the Task Force on Constitution & Bylaws I have been quite busy and we intend to finish our assignment before the next International Epilepsy Congress in Paris. We hope that the new amendments will be useful for ILAE.

In summary, ILAE is growing and is achieving its objectives; I hope it will maintain its progress.

Natalio Fejerman

PAST PRESIDENT



The primary role of the Past President is to provide continuity between the current Executive Committee and the previous one, and periodically to remind current officers that they cannot hope to achieve the wisdom of their predecessors. In addition, the Past President traditionally serves as co-chair of the Global Campaign against Epilepsy (GCAE) with the Past President of the International Bureau for Epilepsy (IBE), and as chair of the Elections Commission.

During this executive term, the IBE co-chair of the GCAE is Hanneke de Boer of Holland, and the two co-chairs, together with Leonid Prilipko, Chief of Neuroscience for the World Health Organization (WHO), make up the Secretariat. This ILAE/IBE/WHO collaborative effort has initiated a number of demonstration projects to reduce the treatment gap in developing countries and results from two, in China and Senegal, are now published. Detailed Regional Reports on epilepsy have also been published from the African region (AFRO) and the Western Pacific region (WPRO), and similar reports are being prepared from the other regions. A WHO Atlas of Country Resources for Epilepsy is near completion, similar to WHO atlases for mental health, and neurological disorders. In addition, the textbook *Epilepsy: Global Issues for the Practicing Neurologist* was recently released by the World Federation of Neurology (WFN) for neurologists practicing in developing countries and will be available for use by the GCAE. During the past term, the GCAE has issued a biannual newsletter, and sessions on the activities of the GCAE have been included in international, regional, and national epilepsy congresses. Also during this executive term, the GCAE has been elevated to the highest priority level within WHO, permitting the campaign to make use of WHO funding, as well as to raise funds in the name of WHO. A major accomplishment of the GCAE during this term, therefore, has been to greatly reduce the cost of this effort to ILAE and IBE, and approximate the goal of making the campaign financially self-sustaining.

The Elections Commission, chaired by the Past President, included Esper Cavalheiro of Brazil, Harry Meinardi of Holland, Amel Mrabet of Tunisia, and Masakazu Seino of Japan. For the first time, the elections were carried out by our executive office in Brussels, and a record number of chapters participated. In the first phase of the election, there were three candidates for President, Martin Brodie of the UK, Natalio Fejerman of Argentina, and Peter Wolf of Denmark, and Peter Wolf was elected to be the next President. In the second phase of the election, there were eight candidates, Fred Andermann of Canada, Michel Baulac of France, Martin Brodie of the UK, Alla Guekht of Russia, Solomon Moshé of the USA, Çigdem Özkara of Turkey, Emilio Perucca of Italy, and Chong-Tin Tan of Malaysia. The new officers will be Emilio Perucca, First Vice President, Fred Andermann, Second Vice President, Solomon Moshé, Secretary-General, and Martin Brodie, Treasurer. All eight candidates received strong chapter support. The League is fortunate to have many potential leaders among its membership, and it is not uncommon for individuals to run for office several times before being elected. We sincerely hope that the candidates who were not elected to office this time will remain active in ILAE and strive for elected office in the future.

Peter Engel

SOLOMON L. MOSHÉ, MD

Secretary General Elect

Currently, I am Professor of Neurology, Neuroscience and Pediatrics, Vice-Chair, Department of Neurology, Director, Pediatric Neurology and Director of Clinical Neurophysiology, at Albert Einstein College of Medicine.

I received my medical degree from the National University of Athens, School of Medicine, Athens, Greece. I am happy to have been the recipient of a number of honors and awards and have served on many international committees aimed at improving the care of patients through translational research. I have organized several International Conferences on 'Brain Development and Epilepsy' and a number of educational courses for young researchers from countries without well-established epilepsy research and clinical delivery systems.

My research has focused on understanding the mechanisms underlying epilepsy and its consequences in children. My current basic and clinical research interests include:

maturational issues in seizure susceptibility and seizure control; role of subcortical systems in the expression of seizures as a function of age and sex; consequences of seizures on the immature brain; development of databases of patients with catastrophic epilepsies and relevant animal models; autonomic dysfunction in epilepsies; identification of predictive or surrogate markers of intractability; genetic/age/sex based treatment issues of epileptic disorders; impact of epilepsies on syndromes of autism and especially Rett syndrome; and the promotion through teaching and basic and clinical research of the best care for children with epilepsy throughout the world.

As an all encompassing principle, I would like to continue the involvement of the ILAE in the Global Campaign Against Epilepsy intended to improve the quality of the lives of people with epilepsy and to break down barriers that interfere with their lives. In keeping with this philosophy I would seek to:



- a) enhance access to care for patients with epilepsy in all countries;
- b) expand access to electronically transmitted information for epilepsy specialists around the world so as to enable them to share their experiences and expertise;
- c) attract the best and the brightest young people into the epilepsy field;
- d) foster world wide collaborative translational research efforts to understand the genetics and pathophysiology of the epilepsies as a function of age and sex;
- e) identify innovative means of translating care with the ultimate goal of curing and, eventually, eradicating epileptic disorders.

As a physician involved in clinical practice, basic and clinical research and teaching, I have a unique perspective on how to incorporate pioneering cost-effective translational research in order to provide better services for patients with epilepsy. Using my expertise in pediatric epilepsies, I plan to work with President Wolf and the Board to develop financially sound and successful partnerships among the Chapters and Governmental bodies to accomplish these goals.

Solomon Moshé

EMILIO PERUCCA

Vice President Elect

The Epigraph editor told me that readers wanted to know something about the lives and careers of the newly elected ILAE Executive members, so I am happy to take up his invitation to write a few notes about myself.

I was born in a small village in Northern Italy. My interest in epilepsy dates from when, as a fresh medical graduate, I was accepted for a brief fellowship at the Department of Clinical Pharmacology of the Karolinska Institute in Huddinge, Sweden. There, a year earlier, Lars Lund had completed his PhD thesis on what became seminal work on the value of monitoring serum phenytoin levels. That kindled my interest in antiepileptic drugs, and a year later I found myself working at the Chalfont Centre for Epilepsy in England, under the leadership of Professor Alan Richens. The six years that I spent with Alan

have been crucial to my career - his teaching and friendship continue to inspire my work to this very moment. Chalfont was very different from what it is today - there were times when I was the only doctor on site, taking care for the health problems, not just epilepsy, of over 600 patients. Chalfont was also a goldmine of iatrogenic disease, which sensitized me to the importance of adverse drug effects on people's quality of life. My early research was focused on pharmacokinetics, both as an investigator and as a guinea pig: I still pride myself of being one of the first humans to have received i.v. valproate, and the second to have enjoyed an i.v. cocktail of radioactive phenytoin with its synthetic metabolite. After returning to my University in Italy in 1981, my interests have increasingly switched to outcome assessment



and therapeutic trials. Over the years, I collaborated with colleagues from many countries, and I consider myself privileged to work in a field where there so many physicians and scientists have truly dedicated their lives to fight a disease that causes so much suffering. I am currently Professor of Clinical Pharmacology at the University of Pavia, and Director of the Laboratories for Diagnostics and Applied Biological Research at the local Institute of Neurology.

On a more personal note, I have a 25-year-old son and a very patient and caring wife, who does not see much of me except when, every August, we go together on mushroom hunting expeditions in a remote corner of the Austrian Alps.

Emilio Perucca

SIMON SHORVON

Outgoing Information Officer



Two projects have been top priority for the work of the Information Officer in the past few years - the **ILAE Website** (www.epilepsy.org) and the Epilepsy Information Center (EIC).

The ILAE website has been developed in two distinct stages. First, the site structure was designed and built and information about the ILAE uploaded. In the second current stage, a range of information about epilepsy is being added. The ILAE sections include information about the League's mission and strategic plan, constitution and bylaws, officers and executive committee, chapters, regions, commissions, task forces, annual reports, publications and conferences, with separate pages for each chapter and also for each region and an archive section.

Adding information about epilepsy is an ongoing task, and to date the following sections are on the site (or about to be so): (a) updated lists of the materials held by the EIC (see below); (b) digitised versions of some video and documentary material from the EIC holdings; (c) a bibliography of books about epilepsy (1945-present); (d) a list of drug names/formulations/preparations in each country; (e) the editor's selection of current articles from scientific journals; (f) a 'hot-topic' section; (g) ILAE reports; (h) Global Campaign; (i) Classification and Terminology Task Force. All these sections are regularly updated and a powerful search engine underpins the site. An interactive discussion group for ILAE members is due for launch in the Autumn. In the next few years, the emphasis will be to continue to add up-to-date and accurate information about epilepsy - and the ultimate goal of the site is to become the première portal for professionals on epilepsy matters.

The website is superbly supported technically by ILAE Hartford office under the able leadership of Joe Wall, and the professional content is overseen by the Information Officer and the Website Task Force. The Epilepsy Bibliography was generously provided by Professor Yukio Fukuyama.

The Epilepsy Information Center (EIC), based in Zurich, is the second important element of ILAE information services. Here, the ILAE collection of epilepsy resources are housed - these comprise about 1500 items concerned with epilepsy (videos, information documents, pamphlets etc). These are now indexed (the index is posted on the website) and stored, and the most generally useful items are being digitally copied for addition to the website. The EIC also provides back-end support for the website, and will be an important element of the planned interactive services. The EIC is excellently maintained in Zurich by Dr Ian Mothersill and his team at the Swiss Epilepsy Centre, and the EIC is co-ordinated and overseen by the Information Officer and the EIC Committee.

The ILAE is a 'family' whose work depends crucially on elements such as collegiality, selflessness, friendship and professional integrity. These principles have been of enormous importance to me personally, and I offer my deeply felt gratitude to those working on the website and EIC, to the ILAE Executive Committee for their wisdom and support, and for the friendship of ILAE members around the world.

Simon Shorvon

ILAE BULLETIN BOARD:

News from correspondents



GREECE

From 21 to 23 October, 2005 the Greek chapter is organising the 1st Hellenic Epilepsy Conference with international participation, in collaboration with the Greek Association and the Cyprus Chapter.

Thanos Covanis



GUATEMALA

In the last year the activities of IBE Guatemala have increased in number and scale, especially because additional subchapters have opened, bringing the number in the country up from 10 in the previous year to 15 this year. Each chapter includes physicians, school teachers, prominent members of the communities, patients and their relatives.

Each subchapter of IBE works alongside a subchapter of ILAE because in Guatemala the activities of IBE and ILAE are fully integrated as both organizations are under the presidency of Dr. Henry B. Stokes.

IBE Guatemala and ILAE Guatemala are working hard on the planning of the next IV Latin American Epilepsy Congress, scheduled for 7, 8, 9, 10 September 2005, and at the same time information about the event is being distributed internationally. The International organising committee of the Congress is presided over by Dr. Henry B. Stokes. The Latin America Epilepsy Day is planned for September 9, 2006.

A month ago as part of IBE and ILAE activities aimed at improving the health system in Guatemala, we represented our organization in a multi-sectorial meeting and face to face discussions with the President of the Guatemala Republic, Mr. Oscar Berger, he offered special help for our organizations with a follow-up meeting.

Henry Stokes



HUNGARY

AMBITIONS, PLANS AND DREAMS

Due to the discrimination that exists in many countries, people with epilepsy continue to require special consideration. There is clearly a requirement for well-considered measures and provisions in law, however, more importantly, there is the need for a change in societal attitudes. One of the most important professional principles regarding equality is the guarantee that all patients receive equal, high quality, and up-to-date comprehensive care.

Since 2003, when the Hungarian Epilepsy League presented a short report of its activities in the Epigraph, we have prepared a professional protocol, including extents and conditions of epileptic care to help with the realization of organizational and financial responsibilities. The epilepsy care protocol defines the scope of duties related to primary, secondary, and tertiary levels of care. The accreditation system created previously by the Hungarian Epilepsy League defines the rules of personal and institutional conditions. Aside from the diagnostic, therapeutic (pharmacological, surgical, and others), rehabilitational, and caregiving recommendations, the protocol outlines tasks according to the psychosocial consequences of epilepsy. The protocol describes collaboration among colleagues of different specialities treating epileptic patients, for example, gynecologists involved in care of women living with epilepsy (family planning, gravidity, delivery, and supporting breast feeding).

We have also established closer cooperation with world reknown neuroscientists involved in epilepsy research from the Institute of Experimental Medicine, Hungarian Academy of Sciences. We continue our efforts to end the stigmatisation of epileptic patients by organizing meetings, using the potential of the media, and establishing Epilepsy Days throughout the country within the framework of the Global Campaign promoted by the World Health Organization (WHO).

Which brings us to the future.

Hungary was among the first nations to join the International League Against Epilepsy (ILAE), with Budapest serving as its birthplace. We would be honoured to bridge the founding of the ILAE and its 100 year anniversary by hosting the Centenarium in 2009.

Judit Jerney

PAKISTAN

EPILEPSY EDUCATION AT ITS BEST

School Awareness Workshops and Epilepsy Poster, Comprehensive Epilepsy Control Programme of Pakistan.

Pakistan has initiated a country-wide programme to deliver public health education concerning epilepsy at the grass roots level, i.e. in the schools. It is being done in the belief that if the teachers and students receive the correct message, not only will they change the perception of illness and thereby reduce stigma, but they will also encourage potential patients to seek medical advice. The programme is phased in two stages. This has already been launched in the three major provinces of the country, beginning with our already functioning Satellite Epilepsy Centres that are run by doctors who have the Diploma in Clinical Neurology.

Hasan Aziz

POLAND

A Polish national session on epilepsy titled "Epilepsy - Go Out and Face Life" was held at the Jan III Sobieski Hotel in Warsaw on 19 February 2005. This was the first national conference for patients with epilepsy.

Krzysztof Owczarek

SENEGAL

FOUR MAJOR EVENTS FOR EPILEPSY IN SENEGAL

1. The setting up of a partnership between SANOFI/AVENTIS and the Senegalese League against Epilepsy. Since March 2005, several

activities have been initiated in Senegal. During 2005 and 2006 "Caravanes pour l'Epilepsie" are being organized in the regions. They consist of two days of activities with a full training day followed, for Medical officers, by a day of consultation for people with epilepsy.

2. A convention has been signed between the French League Against Epilepsy and the Senegalese League Against Epilepsy. France and Senegal have been linked by a long history spanning more than 300 years. This convention sets up a "Sister League" for the exchange and sharing of training and research, and other supportive activities will be developed. Training course will be organized every two years from 2006, with the support of the French League and, probably, of EUREPA.
3. A group of traditional healers (see photo), seeking training on epilepsy were welcomed at the university hospital of Dakar, on Saturday 12 March 2005. This was an extraordinary event, never seen in Senegal and very rare in developing countries. Six hours of discussion allowed neurologists and psychiatrists to make them aware of the burden of epilepsy, to teach them about the anatomy and the physiology of the brain, and to describe the electro-clinical features of epileptic seizures and their modern management.
4. The first on-site completely trained neurologist graduated in February 2005 at the University of Dakar.

Amadou Gallo Diop



SWEDEN

During the last year the Swedish Chapter has organised two workshops, one titled "Catastrophic childhood epilepsy - surgical procedures" and the other one "Functional magnetic tomography imaging in pre-surgical epilepsy evaluation". The annual meeting of the Swedish Chapter was as usual held in November, this year in Umeå and the main topic was "Epidemiology and epilepsy". The chapter also sponsored a national meeting for epilepsy nurses where they discussed ethical problems in relation to caring for patients with epilepsy.

Eva Kumlien

SWITZERLAND

OFFICIAL APPROVAL INSPIRES TRUST

At the end of last year the Swiss League Against Epilepsy was certified by the ZEWOF Foundation (in German: ZEWOF Stiftung: Fachstelle für gemeinnützige Spenden sammelnde Organisationen / organisation for charities collecting money in Switzerland) and received their stamp of quality which evidences the conscientious and economical handling of donations. The ZEWOF qualification provides important information about the League's working methods to sponsors and donors.

RESEARCH GRANTS MADE BY THE SWISS LEAGUE AGAINST EPILEPSY

Research grants are made to support scientific projects in the fields of experimental or clinical epilepsy and epileptology. The projects may be conducted in Switzerland or during a stay abroad by a scientist or clinician active in Switzerland. The grants of up to SF20,000 can be used to cover travel costs, living expenses, operating costs, and purchase of equipment.

This year's grant of SF 16,000 was awarded to PD Reinhard Ganz and Matthias Schmutz lic.phil., both working at the Swiss Epilepsy Centre Zurich, for their study "Personality and effect in patients with epilepsy after selective amygdalohippocampectomy".

Gunter Kraemer

TUNISIA

Since October 2004, Tunisian Association Against Epilepsy (TAAE) has had a new board. The TAAE aims were to advance and disseminate knowledge about epilepsy and to improve services and care for patients; and with the team, we stress the need to promote research, education and training. The TAAE plans to promote a “mastere d'épileptologie” which is a postgraduate diploma for medical doctors.

New directions have also been recently set for the development of international collaborations, and also the establishment of closer relationships with general practice, who actually care for a large majority of patients with epilepsy in Tunisia, especially in the towns with insufficient medical structures.

Chahnez Triki



The program ‘case presentation workshop’ that involves a series of lectures on epilepsy started on 23rd March 2005 and three meetings have been held so far. Sixteen instructors from 13 epilepsy centres all over Turkey will be lecturing during the course of the program.

Candan Gurses



During the American Epilepsy Society 58th annual meeting at New Orleans, a special interest group meeting was held on Epilepsy Surgery in Developing Countries on December 5, 2004. The meeting was coordinated by Dr. Andre Palmieri. Professor Jerome Engel made the introductory remarks. Development of epilepsy surgery in Brazil was presented by Drs. Americo Sakamoto and Eliseu Paglioli. Epilepsy surgery in India was presented by Dr. Malla Bhaskara Rao. There was a group discussion on pressing issues on epilepsy surgery in developing countries. The need to develop epilepsy surgery programs in countries with limited resources was emphasized at the meeting.

Malla Bhaskara Rao

TURKEY

The General Assembly of Turkish Epilepsy Society was held in January 2005. The members of the executive committee were elected.



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All communications should be directed to Juliet Solomon, Editorial Assistant,
6th Floor, Institute of Neurology, Queen Square, London WC1N 3BG, United Kingdom.
Tel: +44 (0)20 7837 3611 (ext. 4285) Fax: +44 (0) 20 7278 5616 Email: j.solomon@ion.ucl.ac.uk

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Tolerance to Beneficial and Adverse Effects of Antiepileptic Therapy

MERRITT-PUTNAM SYMPOSIUM

11th INTERNATIONAL



Le Palais des Congrès de Paris • August 28th 2005

AGENDA

Welcome and Introduction

Richard H. Mattson, MD, Chair

Professor of Neurology, Department of Neurology,
Yale University School of Medicine, New Haven, Connecticut, USA

Do AEDs Lose Their Activity During Prolonged Treatment?

The Evidence From Laboratory Studies

Wolfgang Löscher, DVM, PhD

Professor and Chair, Department of Pharmacology, Toxicology and Pharmacy,
School of Veterinary Medicine Hannover, Hannover, Germany

Do AEDs Lose Their Efficacy During Prolonged Treatment?

The Evidence From the Clinic

Dieter Schmidt, MD

Emeritus Professor of Neurology, Free University of Berlin, Germany,
Head, Epilepsy Research Group, Berlin, Germany

Exploring Potential Clinical Benefits of Tolerance to Adverse Effects of AEDs

Frank Gilliam, MD, MPH

Caitlin Tynan Doyle Professor of Neurology, Director, Comprehensive Epilepsy
Center, Columbia University, New York, New York, USA

Question-and-Answer Session

Sunday 28th August 2005 • 15.00-16.30

Le Palais des Congrès de Paris, Grand Amphithéâtre, Paris, France

To be held during the 26th International Epilepsy Congress



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