

# EpigrapM

THE NEWSLETTER OF THE INTERNATIONAL LEAGUE AGAINST EPILEPSY

ISSUE 1 2002

## President's Message

# Regional Commitment

**This year's congress activity of the ILAE is, and has been, dominated by three regional meetings: Latin America (Iguazu, Brazil, May 29 - June 2), Asia-Oceania (Karuzawa, Japan, September 10-14) and Europe (Madrid, Spain, October 6-10). These meetings are an important part of the activities of the ILAE's Regional Commissions.**

**T**he idea of creating the Commission for European Affairs (CEA) arose from the first European meeting organised in Oporto, Portugal (1994), with the aim of unifying the various supranational initiatives that had previously been restricted to certain European areas with common cultural traditions. The success of the Oporto meeting demonstrated that the European ILAE Chapters were ready to co-ordinate themselves at continental level. This was immediately recognised by the ILAE Executive Committee which subsequently created the CEA as a prototype of a worldwide Regional Commission system. The Commissions for Asian and Oceanian Affairs (CAOA) and North American Affairs were established in 1997 while the Latin American Affairs Commission was established in 1998; a similar type of organisation was foreseen for the African Continent. Now, in order to follow the geographical divisions of the WHO more closely, a further Commission for the Eastern Mediterranean Area is being created.

### Crucial Steps

Regional congresses have contributed significantly towards strengthening the relationships between the Chapters in the various regions and have marked crucial steps in the development of regional strategies: four have already been held in Europe, three in Asia-Oceania and two in Latin America. Europe, which was the first to start regional-based activities, has been seen as a point of reference for the other regions in terms of the definition of rules, and the establishment of educational and training programmes.

Although the different regions have different requirements reflected in their rules, Europe, Asia-Oceania and Latin America have given

themselves a similar type of organisation based on a Council consisting of representatives of all of their Chapters and a Commission with five members elected by the Chapters plus two appointed directly by the ILAE President, who also designates the Chairman and Secretary: Svein Johannessen and Emilio Perucca for Europe, Juvenal Gutierrez Moctezuma and Marcelo Devilat for Latin America, Chong Tin Tan for Asia-Oceania, and William H. Theodore for North America (the Secretaries are still to be appointed). This structure is considered suitable by the ILAE, but is potentially amendable on the basis of any proposals that the Regional Commissions feel appropriate to submit to the



**The impressive waterfalls at Iguazu – the location of the Latin American regional meeting held earlier this year.**

ILAE EC in order to meet their own specific needs. One particular situation is that of the Commission for North American Affairs, which covers a very large and active epileptological community divided into only three Chapters (Canada, Mexico and the USA); furthermore, the American Epilepsy Society (the USA Chapter) has many members from Canada and Mexico and is currently carrying on many activities that could be attributed to a Regional Commission. For this reason, we are evaluating a special regulation for North America that could

## Editorial

Welcome to the latest issue of *EpigrapM*. As always, we are pleased to include the President's Message which can be found on pages 1 and 2.

This issue is varying in content. We have a feature on page 6 detailing the forthcoming 25th International Congress to be held in Tunis in 2003, which promises to be interesting. The ILAE wants to take the epilepsy movement to as many countries as possible and choosing Tunis as the venue for our next congress is a good example of our policy of encompassing all countries and nations in this process. We hope as many of you as possible will be able to attend.

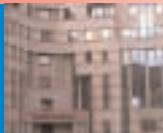
On page 3 we invite you to read about the recent audit into sudden death in epilepsy. This is the first time an audit of this type has been carried out in the United Kingdom, possibly the world. It highlights the urgent need to review services for people with epilepsy.

Finally the ILAE has now an administrative structure set up in Brussels, Belgium. This office deals with all membership issues and should be the first port of call for all members who wish to make enquiries, with the exception of any financial matters which will continue to be dealt with by the financial office in Hartford, Connecticut, USA.

We are still in the process of sorting out the best way to improve the dissemination of *EpigrapM* and in what format. May I extend my thanks to all those of you who responded with your views on how you thought *EpigrapM* should be produced. We are always striving to find ways of including what you want in *EpigrapM*. Any suggestions, as ever, will be most warmly welcomed (contact details on the back cover of this issue).

Ley Sander, Editor

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involve the three Chapters in a more direct way than in other regions.

### Strategic importance

I have given this account of the development of the ILAE regional system not only because the details might not be known to every ILAE Chapter member, but also to underline the strategic importance that the present Executive Committee attributes to the Regional Commissions. The progressive increase in the number of Chapters throughout the world makes it increasingly important to strengthen an organisational model that respects the independence of the Chapters while simultaneously guaranteeing their involvement in the planning and conduct of ILAE activities. The Regional Commissions are already promoting this development by taking advantage of their direct knowledge of the culture, organisational level and specific needs of their areas in order to facilitate communications between the ILAE and its Chapters. To this end, close interactions between the Regional Commissions and Councils needs to be encouraged in order to ensure that every Chapter can voice its views.

### Other initiatives

The advantages of such an organisation have already been demonstrated by the documents describing epilepsy-related regional issues, and by the educational initiatives and special programmes being

undertaken in the different Regions. The Regional Commissions have contributed substantially towards establishing new ILAE Chapters in countries where they did not previously exist and, by means of the organisation of increasingly successful Regional Congresses, have effectively promoted exchanges of experiences and collaborative programmes among the members of the different Chapters belonging to the same region.

### Subsidy

The ILAE Executive Committee has established an ad hoc task force (chaired by the 2nd ILAE Vice-President Martin Brodie) in order to assist the Regional Commissions and seek advice from them about ILAE policies. One practical result of the special attention being paid to regional activities is the allocation of a special contribution of \$25,000 to both the Asian-Oceanian and Latin American congresses to subsidise a bursary program aimed at facilitating the participation of young students and/or delegates from economically disadvantaged countries. In addition to encouraging long-term regional planning, it has been decided that, at the end of their four-year terms, the Regional Commissions may carry forward any residual money that will be reallocated in their new term budget.

### Completion

The ILAE is now committed to completing the regional system by creating the two missing Regional Commissions (African

and Eastern Mediterranean). It is expected that this process, which is currently going on in consultation with the Chapters involved, will be finalised before the next International Congress in Tunis, a place that has particular significance for both Regions.

Furthermore, the Regional Commissions are still engaged in recruiting new Chapters that will help to fill some of the gaps in the geographical coverage of the ILAE in sub-Saharan Africa and Asia: for example, we are still not represented in the People's Republic of China, which accounts for one-fifth of the world's population. Completing our worldwide coverage will be one of the most important achievements of the present ILAE Executive Committee.

Restrictions on space don't allow me to mention many other major activities and initiatives of the League in this issue. However many of these are featured on our web site ([www.epilpesy.org](http://www.epilpesy.org)) - an important achievement in itself. This will be the focus of my contribution to the next *Epigraph*, whose editorial team should also be congratulated on bringing the voice of the ILAE to our members in such an effective and professional format.

**Giuliano Avanzini,  
President, ILAE**



## Bringing industry to the conference table

The need for comprehensive and coherent guidelines for the participation of Industry in International and Regional Epilepsy Congresses has long been recognised. Detailed work has been undertaken in recent months with a view to finalising guidelines for all ILAE/IBE Congresses. There was a general consensus that the production of an enduring guideline document could only be achieved through an open discussion forum with industry representatives, at which all views relating to the manner in which congresses are conducted can be expressed.

To this end, a round table meeting was held in March 2002 between the joint committee of ILAE/IBE and representatives from major Pharmaceutical Companies. The purpose of the meeting was to discuss changes to the draft Industry Guidelines in order to establish an agreed guidelines template. The ultimate aim of the Guidelines is to establish a long-term and consistent definition of standards for Industry participation in congresses, and to regulate for all commercial interests at ILAE/IBE Congresses.

The Guidelines will set out a framework for industry's long-term involvement in and financial support of ILAE/IBE congresses. They will also reflect the mutual commitment of ILAE/IBE and industry to congresses at which the main objective is to produce high scientific content within an acceptable cost structure.

Although these guidelines will remain fluid in their make-up as influences and general requirements change over time, the importance of having an agreed starting point from which to base future decisions and organisational frameworks has been acknowledged by all parties.

Members of the Joint Executive Committee of ILAE/IBE said that they felt that this joint framework of co-operation and communication was working very well and the Committee should continue working with Industry in this manner.

Industry representatives at the meeting commented that they were reassured by the general atmosphere of partnership which has been elicited by the ILAE and IBE and were very supportive of the collaborative process which has now been put in motion with regard to the Industry Guidelines.

It is envisaged that an agreed set of Guidelines will be in place in the near future, a development which will ultimately serve to ensure continued high scientific standards and value for delegates at all ILAE/IBE Congresses.

**For further information on the guidelines for industry participation in ILAE & IBE International & Regional Congresses contact the office of the International Director of Meetings:  
Tel: +353 1 409 7796 e-mail: [tiiec@indigo.ie](mailto:tiiec@indigo.ie)**

# Epilepsy Deaths in the Shadows: A call for action!

**People with chronic epilepsy are between 2 and 3 times more likely to die early than those without epilepsy. Some of these deaths are due to *status epilepticus*, accidents and drowning, but more are due to Sudden Unexpected Death in Epilepsy (SUDEP).**

It is not entirely clear what causes SUDEP, but the most important risk factor is the occurrence of seizures – and the more frequent the seizures, the higher the risk. Over the last fifty years, five UK government reports have recommended improvements in medical care for people with epilepsy, but little has changed, and concern still exists about standards of care. Since most deaths are related to seizures, the UK government commissioned an audit aimed primarily at establishing whether there was potential for prevention of deaths through improvements in care.

## Survey results made public

The results of the National Sentinel Clinical Audit of Epilepsy-Related Deaths (Epilepsy Deaths in the Shadows), were made public recently. The audit was managed by the NGO Epilepsy Bereaved, working in partnership with organisations representing clinicians and pathologists and was coordinated by, amongst others, David Fish and Ley Sander, as representatives of ILAE. The audit looked at all the deaths, and reviewed the records of a sample of the approximately 1,000 individuals who died of an epilepsy-related death in the UK during a 12-month period in 1999/2000. It was estimated that 60% of the deaths were SUDEP. Audits were performed on the investigation of death, and both primary and secondary care prior to death.

A striking point was that the investigation of the majority of the deaths involving a post-mortem was considered inadequate, and the stated cause of death was inconsistent and, in some cases, inappropriate. Also of concern were a number of deaths which were sudden, but were certified by doctors without post-mortem investigation. As SUDEP is a catastrophic event whose causes are inadequately understood, it is important that investigation into deaths should be consistent and thorough.

There was little documented contact with relatives after a death by health professionals. Contact with relatives is particularly important

because many deaths are sudden and unexpected and families experience bewilderment, isolation and prolonged distress and can be helped with information and support.

## Poor clinical note-keeping

One of the main findings in primary care was the poor clinical note-keeping. For many patients with recent onset of seizures, both the time taken to be referred and the time to first specialist appointment were too long; some died while waiting for a hospital appointment. Of those whose clinical notes suggested re-referral to specialist care was indicated, only 9% were re-referred. There was little evidence of management plans, and the review process in primary care was unstructured and lacking in detail. Most reviews were simply to provide medication or to check blood levels of the drugs. Information provision was documented in only a quarter of cases. Only 1% of patients had been given information on the risk that seizures could be fatal, even amongst those individuals in this audit whose epilepsy required ongoing care and who had many apparent risk factors.

## Information provision poor

The secondary care audit showed that less than two thirds of adults who were not seizure free had been seen in a hospital clinic in the year before death. Almost one fifth of adults appear to have been lost to follow-up, and the management of people not attending appointments was variable. A seizure description and frequency were lacking in around one fifth of secondary care notes. Over a third of adults

had no brain imaging, with similar figures for EEG studies. Information provision was again poor. The topics recorded were most likely to include side effects of medication, type of epilepsy, social factors and leisure rather than importance of taking medication, hazards of seizures and only 1% adults appear to have been told that seizures could be fatal. Over half of adults were classified as having had inadequate care, or care in which there were

major errors. Death was classified as potentially or probably avoidable in over a third. Inadequate access to outpatients, inadequate investigations, and therapeutic management were the main causes of the failure of care.

The secondary care audit classified over three quarters of the children as having had substandard care; this was due to inadequate access to a consultant, lack of investigations and poor AED management. Death was classified as potentially or probably avoidable in over half. Documented information provision was scarce.

The report concludes that epilepsy-related death, and particularly SUDEP, is still underestimated by healthcare professionals. There was concern about many aspects of epilepsy management, particularly access to specialist care, management received and information provision. This situation, in a developed country with a well-established healthcare system, leaves a lot to be desired. A commentary in the *Lancet* suggests that the audit should be a wake-up call for epilepsy management around the world and indeed in some countries outside of the UK the report has already been used to highlight concerns about epilepsy care.

## A call to action?

In the UK there is evidence that the report has already raised the profile of epilepsy and has triggered a commitment by the government to consider what actions can be taken now to reduce epilepsy deaths. The National Institute of Clinical Excellence (NICE) which is a body responsible for improving national standards has indicated that health organisations should not wait for national plans to review their management of epilepsy services and epilepsy deaths. NICE has promised to take the report forward in the development of national epilepsy guidelines and appraisal of drugs for epilepsy. In addition, the Chief Medical Officer has already written that he intends to develop an action plan to reduce the level of preventable deaths from epilepsy within three months of the publication of the report.

**The full and summary report can be found on: [www.SUDEP.org](http://www.SUDEP.org)**

*“To show my very real commitment to this important issue, I intend to develop an action plan to reduce the level of preventable deaths from epilepsy within three months of publication of this report. I am pleased that work has already begun.”*

**Sir Liam Donaldson  
Chief Medical Officer  
for England**

*“No one knows why Simon died because, although epilepsy is the most common neurological brain disorder in the world, it is also the most neglected.”*

**A mother writing after her son died, aged 31**

# New HQ heralds improved service to members



The Brussels office where the ILAE headquarters are housed.

Centralising the League's administrative functions to improve membership services was an important consideration when the Executive Committee researched its options on setting up a headquarters office.

As the administrative needs of the organization have expanded, more and more volunteer time has been spent managing the day-to-day operational details while increasingly less volunteer time has been spent directing and servicing the projects that meet the objectives of the ILAE. Establishing a centralised administrative office to manage the operational details has already proved effective and is allowing the Executive Committee more time to focus on the League's objectives, which are:

- To advance and disseminate knowledge about epilepsy;
- To promote research, education and training; and
- To improve services and care for patients, especially by prevention, diagnosis and treatment.

An equally important factor was to provide the ability to respond to members with a staff that spoke multiple languages, was sensitive to cultural differences and was located in a politically neutral country. The staff and location of the new HQ fulfill this requirement successfully.

ILAE President, Prof. Giuliano Avanzini says, "This is certainly an exciting change that will enhance the services provided to the League's Chapters and reduce the Executive Committee's administrative burden. Already I am seeing improvements and am pleased with our decision to establish a headquarters office."

**In a strategic move that benefits its members, the ILAE has established a new administrative headquarters in Brussels, Belgium. The new office provides services that were previously not available or only offered on a volunteer basis. In addition to the support of the Financial Office, based in the United States, the League now has staffing to support most of its administrative needs.**

## At your service!

The new headquarters began servicing the League on January 1, 2002. Their primary role is to provide centralised contact for all chapters and to be the central location for all League correspondence and archives. Servicing the needs of the Executive Committee, the headquarters staff provide administrative support for all Executive Committee functions and attends all of their meetings.

The Brussels office is not new to the association management field and already services other non-profit organisations. Managed by Ernst & Young Association Management who are already familiar with the issues that face international organisations, the office is able to support the League with staff that is multi-lingual and well versed in non-profit management. ILAE's Assistant Administrative Director is Delphine Sartiaux. She is supported by Nele Devolder.

## Gathering information

ILAE Headquarters is busy gathering accurate chapter contact and membership information. This will support the League's efforts to increase contact with, and services to, its chapters. Much of the contact that was once handled by the League's secretariat will now be managed at the Headquarters office. The League's Secretariat, Prof. Natalio Fejerman, will be involved in all membership matters but will no longer have to respond to the more mundane tasks of updating the database and sending out notices.

"This change is a positive one for ILAE and the office of the secretariat," states Prof. Natalio Fejerman. "I am able to focus on the work that makes a difference for the League and our profession while staff answers calls and ensures that the database information is

correct. If something comes up that needs my attention, they notify me immediately."

All chapter leaders should note the contact information for the ILAE Headquarters, which is:

**Avenue Marcel Thiry 204,  
B-1200, Brussels, Belgium,  
e-mail: [info@ilae-epilepsy.org](mailto:info@ilae-epilepsy.org)  
Fax: +32 (0) 2 774 9690  
Tel: +32 (0) 2 774 9547**

## Financial support in the US

The League's financial office is based in West Hartford, Connecticut, USA.

Peter J. Berry, the League's Financial Manager has also taken on the role of Administrative Director and is responsible for the overall management of administrative staff at the Financial Office in the US and Headquarters in Belgium.

The US office continues to provide financial support, maintaining and managing all of the ILAE's financial matters in conjunction with the League's elected Treasurer, Prof. Ley Sander.

"Having professional financial staff has improved my value as Treasurer because I can focus on developing procedures, investing funds, and developing budgets. The office administers deposits, wire transfers, and other daily financial tasks. Staff have the financial training and background so necessary in today's global economy. It's great having their support." says Prof. Ley Sander.

The ILAE Financial Office is located at:

**342 North Main Street, West Hartford,  
CT, 06117, USA.  
Fax: +860/586-7550  
Tel: +860/586-7547**

# The ILAE Administrative Team



**PETER BERRY** is the Administrative Director and is responsible for ILAE staff at both offices.

Based in the Financial Office, Peter has been working with the ILAE since 1997. With a masters degree from Northeastern University in Boston, MA, he also earned certification as an association executive from the American Society of Association Executives. Peter works closely with the League's President, and the Management and Executive Committees.

**[pberry@ilae-epilepsy.org](mailto:pberry@ilae-epilepsy.org)**



**CHERYL KARLON** is ILAE Financial Manager based in the US.

Cheryl earned her degree from Western New England and is working on her MBA for International Business. All requests for reimbursement, wire transfers and budget information should be forwarded to Cheryl. She attends Executive Committee meetings and supports the Treasurer.

**[ckarlon@ilae-epilepsy.org](mailto:ckarlon@ilae-epilepsy.org)**



**DELPHINE SARTIAUX** is the Assistant Administrative Director, and is based in Brussels, Belgium

Delphine earned her degree at the Business School ICHEC in Brussels, Belgium and has five years' experience in the management of associations. She speaks fluent English and French and has a good working knowledge of Dutch. Her role with the League is primarily to assist the Executive Committee officers and the Commission Chairs. Delphine attends Executive Committee meetings and some of the regional/international congresses.

**[dsartiaux@ilae-epilepsy.org](mailto:dsartiaux@ilae-epilepsy.org)**



**NELE DEVOLDER** is a member of the Brussels Headquarters office and supports the Assistant Administrative Director.

Nele is the point of contact for ILAE chapters and their members. After her studies in business communications, she gained experience in office management for international organisations. Nele speaks Dutch, French, English and German.

**[ndevolder@ilae-epilepsy.org](mailto:ndevolder@ilae-epilepsy.org)**



**LORNA BOLDUC** is the Project Manager based in the US.

Lorna is a graduate of Clark University, Worcester, MA. She works directly with the League's Web Task Force on the development and maintenance of the ILAE web site. Lorna also liaises with the Executive Committee as required.

**[lbolduc@ilae-epilepsy.org](mailto:lbolduc@ilae-epilepsy.org)**



All matters regarding the subscription database, sending out dues, subscription notices, the receipt of subscription payments and liaising with Blackwell Science, the publishers of *Epilepsia* should be directed to Karen Breseman.

**[kbreseman@ilae-epilepsy.org](mailto:kbreseman@ilae-epilepsy.org)**



# A Message from Tunisia – the host of the 25th International Congress

**Tunisia will be the destination for the 25th International Epilepsy Congress which is to be held from 12th -16th October 2003. Conference organisers look forward to welcoming epileptologists from around the world to participate in the conference programme and to share the meeting opportunities with colleagues that the conference will provide.**

**T**unisia is a land of colour, contrast and history – its attractions for the visitor would do justice to a country twice its size. If you get the opportunity you can experience everything from stone-age settlements near the oasis at Kebili to the space-age backdrops of Star Wars (parts of

which were filmed at Matmata). Spend a few days here and you'll wonder at the famous Roman ruins of Carthage, while a day's dawdling on the north coast's beaches will leave you wondering why Hannibal ever left!

Whilst tourism remains very low-key throughout most of the country you are sure to be impressed with what you find in Tunisia.

The conference is to be held in Tunis - a modern expanding city that is neither very Arab, nor African. It is not truly

European either but is a highly functional, effective and clean city that successfully mixes the old and the new; with some of the flavour of the former French protectorate and the Suq, typifying the best of the Arab world.



## Principal sites of interest:

**Carthage** founded in 814 BC by the Phoenicians is the most representative site of all the influences that have shaped Tunisia. Carthage has been ruled by glorious conquerors such as Dido, Hannibal and Julius Caesar.

**Sidi Bou Saïd** a lovely white and blue village perched on the cliffs overlooking the Bay of Tunis.

**Kairouan** and the **Great Mosque** first built in 670 by the famous conqueror, Okba Ibn Nafaa whose cultural and scholastic influences extended to Europe and Asia.

The **Amphitheatre El Jem** founded during Julius Caesar's reign is one of the most important Roman monuments in Tunisia.

The **Bardo Museum**: 3,000 years of history in one place - The Bardo Museum holds one of the largest collections of Roman mosaics in the world.



## Women in Tunisia

The following recent quotation from the Washington Times illustrates how often the view of the position of women in a Muslim country is misconceived;

*"The situation of women in Tunisia is often a pleasant surprise for first-time visitors. Tunisia shatters all expectations and preconceived ideas regarding the place and the role of women in a Muslim country. . ."*

The following statistics illustrate the significant role women play in Tunisian society. As a percentage of the total population women represent;

- 48 % of university students,
- 23% of magistrates,
- 35 % of doctors,
- 63 % of pharmacists

## A personal address from Professor Amel Mrabet:

*"It gives me a great pleasure to invite you on behalf of the ILAE, IBE and the Organising Committee, to attend the 25th International Epilepsy Congress to be held from 12th to 16th October 2003 in Tunis, Tunisia. The congress in Tunis promises to be an extremely topical and relevant event and please remember that Tunisia is only 1- 2 hours' flight time from Europe!"*

**Prof. Amel Mrabet, Chairman of the IOC, Chairman of the SAC**



## TUNISA – FACTS AND FIGURES

### Geography

Tunisia is located in Northern Africa, bordering the Mediterranean Sea,

- Surface area: 162,155 square kilometres; 25,000 square kilometres desert; 300 kilometres Mediterranean coast.
- Population: 9 million
- Capital City: Tunis
- Official Language: Arabic. But most Tunisians understand and speak several languages such as French (as a second language), English, Dutch, Spanish and Italian.
- Money: The currency is the Dinar which is equal to 1.5 US\$.

### History

Stretches back over 3,000 years of history and has been the crossroads of civilisation with occupation by the Berbers, Phoenicians, Romans, Punic, Vandals, Arabs Islamic, Spaniards and French .

2,500 archeological sites exist in Tunisia alone.

2.5 million of Tunisia's five million tourists visit cultural sites each year.

Seven monuments and sites on the UNESCO world heritage list.

## Famous People with Epilepsy

# Lewis Carroll Through the Looking Glass

By Dr Nick Krasner

**For a shy, Victorian, erratic man, Lewis Carroll is quoted more commonly than in any other work apart from the Bible and Shakespeare. As well as his novels, he invented many games including Doublets, which is similar to a modern form of Scrabble. He was unaware of the diagnosis of epilepsy until his later years.**



**B**orn Charles Lutwidge Dodgson in Cheshire England, in 1832, he is best known for his creation 'Alice's Adventures in Wonderland'. He was educated at Rugby school and Oxford University where he both studied and lectured on mathematics.

He had a keen interest in children, and wrote thousands of letters to them; delightful flights of fantasy, many illustrated with little sketches. In 1865 he published Alice's Adventures in Wonderland, then Through

the Looking-Glass and What Alice Found There, appeared in 1871, followed by Phantasmagoria and Other Poems (1869).

At the time of his writing, Lewis Carroll was not aware that he suffered from epilepsy. He was diagnosed later on in his life. Carroll's Wonderland and Looking-Glass adventures have been recognized as "fictionalized accounts of seizures". Carroll suffered from complex partial, or temporal lobe epilepsy, which is considered by some to have a psychological effect on the brain. Wonderland and Looking-Glass Land suggest an alter-reality, a possibility for what reality could be.

Alice's method of transport, as floating, describes a common sensation in complex partial seizures. The descriptions of falling down the rabbit hole and the feeling of changing size are directly related to seizure experiences. 'Alice in Wonderland Syndrome' incorporating distortions in body image and shape, often with a impaired perception of time and place, is also associated with epilepsy

Many other aspects of Lewis Carroll's life influenced his writing, including his mathematical background and logical disposition, interest in children, sleeping difficulties, Victorian lifestyle, and neglected childhood. He had an obsessively negative association with eating which could have been drawn from his neurosis (The consequence of Alice eating and drinking is a change in her size). He was thought to have a dual personality, which he characterised into Tweedledee and Tweedledum who constantly contradict each other's opinion.

It seems that this eccentric man's amazing psychology, allied with his life long affliction with epilepsy enabled him to write some of the greatest fiction of all time. Lewis Carroll died in Guildford, Surrey, on January 14, 1898.



### 56th Annual Meeting of the American Epilepsy Society

December 6-11,  
2002

Washington State  
Convention  
& Trade Center  
Seattle, WA



The AES meeting consists of lectures, courses, poster and platform presentations, satellite symposia, commercial exhibits and scientific exhibitions. This meeting offers members and non-members a forum for communicating and disseminating current findings in the field of epilepsy, and is an excellent opportunity for networking and sharing of ideas.

The meeting is designed for the academic and practicing neurologist, neurophysiologist, epileptologist, neuroscientist, neurosurgeon, internist, pediatrician, pharmacist, nurse, social worker, and other allied health professionals.

Over 900 poster and platform presentations, lectures, satellite symposia scientific exhibitions and commercial exhibits are offered.

The conference brochure, with comprehensive conference and hotel registration information and a schedule of programs and events will be mailed to AES members in July. Meeting and hotel reservation information will also be available on the AES web site at [www.aesnet.org](http://www.aesnet.org) or the AES office:

Phone: (860) 586-7505

E-mail: [info@aesnet.org](mailto:info@aesnet.org)

Fax: (860)586-7550

Fax-on-Demand: (860) 586-7575

# Diary Dates

If you would like to publicise an event taking place in your part of the world which would be of interest to ILAE members, we would be happy to receive the relevant information. Please provide date, venue, subject and contact details including contact person, address, telephone/fax number, email address and web site. Please forward this information to the Epigraph office (details below).

## 56th Annual Meeting of the American Epilepsy Society, Washington State Convention & Trade Center, Seattle, WA, 6-11 December 2002

For further information contact:

Tel: +1 860 586-7505 Fax: +1 860 586-7550  
Fax-on-Demand: +1 860 586 7575  
e-mail: info@aesnet.org  
www.aesnet.org

## 1st Sharm El Sheikh Epilepsy Conference, Hyatt Regency Hotel, Sharm El Sheikh, Egypt 5-8 March, 2003

For further information contact:

Dr. Hassan S. Hosny, Cairo University,  
21 El Mansour Mohamed St., #17  
Zamalek 11211, Cairo, Egypt.  
Tel: +20 2 303 3338 Fax: +20 2 304 7117  
e-mail: hhosny@internetegypt.com

## Epilepsy, Neurobiology and Religious Creativity, Vadstena, Sweden, 20-22 March 2003

The relationship between neurological disorders and religious visionary inspiration has been under discussion in scientific circles during the last decades. The Swedish Chapter of the ILAE and Linköping University support the conference.

Scientific programme. The main themes are: The temporal lobe and its function; Expressions of religious revelations; Great men and women with epilepsy; Epilepsy in literature and art; Neural correlates of religious experience; Dreams and visions.

For further information contact:

Professor Birgitta Söderfeldt,  
INR/Dept of Neurology, Linköping University,  
SE-581 85 Linköping, Sweden

e-mail: epilepsy2003@inr.liu.se

http://infoweb.unit.liu.se/hu/inr/conference2003/presentation

## 4th Spring Epilepsy Research Conference, Marriott Grand Cayman Beach Resort in Grand Cayman, BWI, April 26-May 3, 2003

The scientific program is being organised and will be posted soon at

<http://www.caymanconferences.com/epilepsy/>

Session suggestions are welcome.

## 25th International Epilepsy Congress, Tunis, Tunisia, 12-16 October 2003

For further information contact:

ILAE & IBE Congress Secretariat,  
16 Mountdown Road,  
Walkinstown, Dublin 12  
Ireland

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## The 7th Eilat Conference on New Antiepileptic Drugs (Eilat VII), Eilat, Israel (with a backup site in Italy), May 9 – 13, 2004.

The program is designed to provide critical reviews and updated information about new anti-epileptic drugs (AEDs) that are in different stages of development, as well as to present progress reports on recent findings concerning marketed new anti-epileptic drugs. In addition, sessions will be devoted to Advances in the Pathophysiology of Drug Resistance; New AEDs in Paediatric Epilepsy Syndromes; Modes of AED Action and Spectrum of Adverse Effects; A Re-appraisal of Comparative Responses to AEDs Combinations.

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# Bulletin Board

## News from correspondents ...

### ITALY



#### Venice Epilepsy Summer School

The first summer course *Bridging the Gap between Basic and Clinical Epileptology* took place in Venice in July and August this year. The course consisted of didactic lectures, special seminars, practical sessions and tutorials finalised to the preparation of research projects from the students. In addition the students were active in presenting posters and preparing journal clubs. 32 countries were represented in this, the first event which has been established as the Venice Epilepsy Summer School. Full details of the next course in 2003 will be published in the next issue of *Epigraph*.

*Prof. Giuliano Avanzini*

### SWEDEN



During 2001 the Swedish chapter has held two workshops. The main topics were "cortical malformations" and "EEG – a diagnostic tool in epilepsy management". In co-operation with the Swedish epilepsy foundation a national meeting was held in Gothenburg in November. The development and quality of clinical care and science was discussed together with politicians.

*Dr. Eva Kumlien*

### SWITZERLAND



In the process of restructuring the Swiss chapter of the ILAE, the General Assembly of the Swiss League Against Epilepsy has approved new statutes in order to adapt the organization's charter to international standards. Special emphasis was placed upon the information of the public on medical, psychological and social aspects of the illness, the collaboration with other institutions and the support of people with epilepsy. Together with the newly formed IBE chapter of Switzerland (epi-suisse), the Swiss League Against Epilepsy is organizing the first national "Day of Epilepsy", launching the "Swiss Epilepsy Report" on the same day. Numerous activities will take place on the 5th of October, a date chosen to parallel the German "Day of Epilepsy". The annual event should help raise awareness of the situation of people with epilepsy in society.

*From our Swiss Correspondent*

### TURKEY



The third National Epilepsy Congress which was extensively attended by residents, neurologists and epileptologists from all over Turkey, was held in Trabzon, a city in the north eastern part of Turkey from 8-10 June 2002. At the successful congress there were concurrent sessions for each Epibase; a patients database, genetics and education commissions and EURAP; a European registry of AEDs and a pregnancy study group. In these groups completed projects were presented and discussed. Various proposals were put forward for future projects. Online discussion groups via a web site were formed. The first two groups were clinical and neuroscience based. The third was for patients to communicate with each other and share their problems, experiences and inform each other about social activities.

*Dr. Candan Gürses*