In last issue of Epigraph, we reported upon the establishment of a network of correspondents from each national chapter. Their task is to provide local information and to improve the two-way communication between the members and central administration of the ILAE. On pages 6 and 7, we are pleased to present the first fruits of this endeavour: the results of a survey carried out by the correspondents into aspects of the Treatment Gap and drug prescribing practice. The Treatment Gap is perhaps the greatest challenge that the worldwide epilepsy community faces. On page 5 there is also a report of the first ILAE workshop on this subject held recently in Marrakech.

We also include an update on the Global Campaign (page 3), and on page 2 an article from our treasurer, Giuliano Avanzini describing the recent changes to the ILAE financial office and proposed changes to the dues system. Our finances are now in excellent shape, and we all owe Giuliano Avanzini and his team a great debt of thanks for their work in greatly improving the structure and functioning of our financial base.

Our regular features include the Bulletin Board and the Diary Dates. Both are readers’ pages, and we encourage members to send in information for inclusion.

Simon Shorvon Co-Editor
The ILAE Treasurer Reports...

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The ILAE Treasurer’s office has now been moved from Los Angeles to Milan, where it is based at the Instituto Neurologico C. Besta. A new financial office has also been established with a professional staff at Association Resources (Hartford, CT, USA) working in close contact with the Treasurer’s office in Milan. The transition from the previous system to the new one was completed in the second half of 1997, thanks to the helpful collaboration of the previous Treasurer Jerome Engel, Jr and his administrative assistant Betty Crockford. The decision to base the financial office in the USA is particularly appropriate since ILAE is incorporated in the District of Columbia as a publicly supported organisation exempt from federal income tax according to US law. Association Resources has all the necessary expertise to guarantee that financial records comply with legal requirements verified by periodic official audits. It also contributes to the current management of the Treasury by handling, routine ILAE financial matters, i.e. bank statements, preparation of monthly financial reports, etc. The US office offers ILAE a wide range of support: it invoices and processes the Chapters’ dues payments, and it also handles the Epilepsia subscription process which includes invoicing and processing discounted subscriptions to ILAE Chapter members, liaison with the Epilepsia publisher, and sending electronic labels to the publisher each month.

Much effort has been devoted to promote close contacts with Chapter officers and individual members by making it easy to access the Milan office directly by phone, fax and e-mail. The contact person in the Milan office speaks Spanish, German and French besides English (and, of course, Italian).

The People behind the Scenes

At the Milan office, the Treasurer is helped by the administrative assistant, Metella Paterlini, who is a certified translator and has 12 years’ work experience in the field of medical administration. Besides Ms Paterlini, Simona Carattini, Maria Teresa Pasquale and Giovanna Castelli co-operate with the Treasurer in dealing with the ILAE Chapters and individual members.

The primary personnel involved with ILAE’s US office are Peter Berry and Joanne Hoerner. Mr Berry supervises the work, is a liaison for the ILAE Officers, and attends the ILAE Executive Committee meetings as required. Ms Hoerner maintains the ILAE financial records, reconciles the bank accounts, produces the monthly financial reports, and responds to requests. Mr Berry is President of Association Resources, Inc., which he founded in 1983. He has 20 years’ management experience and earned a bachelor’s degree in political science from Northeastern University in Boston, MA. He has participated on several ASAE committees and served as Chair of the 1996 Annual Advisory Committee Meeting and the Evaluation Committee. He also conducts evaluations of associations on a voluntary basis for ASAE.
After eight years in the banking industry, Ms Joanne Hoerrner joined Association Resources in 1993 as a Financial Administrator. She has a general banking degree and a supervisory skills certificate in banking.

Access to the Services

Thanks to the new organisation, the Treasury is able to provide services as needed. The staff are professionals, each with training and experience in their selected fields. The software and hardware are among the best on the market and each package is integrated or compatible, avoiding double entry or costly human error.

New Initiatives

The Treasurer presented the ILAE Executive Committee with a proposal to change the system of calculating the payment of dues. This is because, for some Chapters in the developing world, the present rate of $US3.00 member exceeds the national Chapter fees and makes it impossible for the Chapter to comply with the ILAE rules.

According to the proposal, the annual dues should be calculated as a fixed percentage of the individual national membership fee, rather than a fixed amount of $US3.00 member. The percentage should be equal to the one paid at present by the country with the highest national membership fee (Germany), corresponding to the lowest percentage rate. This rate should then be applied to all the other Chapters.

The proposal was favourably discussed at the meeting of the ILAE EC in La Jolla (5 December, 1998) and reviewed at the ILAE EC meeting in Basel. A formal decision will be presented at the General Assembly in Prague in September 1999, which will have to vote on and ratify the new dues system. Comments and suggestions from Chapters and individual members on this and other matters that may be relevant to improve the Treasurer’s action are welcome.

Financial management is instrumental to ILAE activities: several projects are already ongoing, aimed at raising the general awareness and understanding of epilepsy; improving the management and services for people with epilepsy in developing countries; evaluating the social costs of epilepsy care; setting diagnostic and therapeutic guidelines; and defining professional educational programmes. Thanks to available resources these projects can be pursued and developed to further achievements, while new action plans can be instigated. Our mission is to create the highest standards of care for people with epilepsy worldwide.

Giovanni Avanzini, MD
Treasurer

Global Campaign Update
Towards 2000 . . .

During the second half of 1998, the WHO experienced a major reorganisation under its new Director-General, Dr. Gro Harlem Brundtland from Norway. The ILAE/IBE/WHO Global Campaign Against Epilepsy has emerged from this process reinvigorated. Neurology and neuroscience are now part of a new “cluster” of divisions under the direction of Dr. Yasuhiro Suzuki from Japan who met with members of the Global Campaign Board in December and February. With the support of the Board, Dr. Suzuki is submitting a proposal to the new “Cabinet” of WHO for a major boost and “relaunch” of the Campaign in 2000. Epilepsy is now a high priority in WHO and the leading edge of neurology. In December all the Neuroscience NGOs, chaired by Professor James Toole of WFN, gave their full support to the Campaign.

The Campaign has global, regional and national dimensions that are interdependent. At the global level, the major objective is to persuade the General Assembly of WHO to recognise epilepsy as a global health priority and designate a global Epilepsy Awareness Day. The General Assembly responds to the wishes of national governments and delegates. It is, therefore, vital for ILAE and IBE national Chapters not only to organise their own “Out of the Shadows” Campaign for the benefit of their people with epilepsy under the umbrella of the Global Campaign (see below), but for the Chapters to persuade their own Health Ministers and WHO delegates to support the global objectives. Some 20 countries are already developing their own national campaigns.

At the regional level, demonstration projects are being developed in a few selected developing countries with the assistance of Professor Ley Sander and the regional WHO offices. This is being done with a view to reducing the Treatment Gap and the psychosocial and economic burden of epilepsy and improving education, training, health care delivery and public attitudes. In the PAHO region, Panama and Jamaica are developing plans. In Africa, Senegal and Zimbabwe have been selected. In China, there is a plan to build on a regional community control project that has been completed. These projects will be models for other countries in their region and elsewhere.

Epilepsy is a neglected problem even in developed countries. In October, over a hundred leading representatives of the European Chapters and regional WHO offices met in Heidelberg under the sponsorship of the German Government. They prepared a European Declaration calling on the governments of Europe and the European Union to join in decisive action to meet the objectives of the Global Campaign. This is a model for other regions. A similar meeting for Africa is planned in Senegal early in 2000.

The outcome of the Campaign will depend on co-ordinated actions at global, regional and especially national level, supported by the resources of ILAE, IBE and WHO, and other emerging partners such as UNICEF. The Campaign co-ordinating office and administrative offices of ILAE, IBE and WHO can help you with:

- Political contacts, through WHO, UNICEF, governments
- Public awareness information and contacts
- Educational materials
- Epidemiological information and methods
- Methods of local needs assessment of people with epilepsy
- Models of epilepsy services (primary, secondary, tertiary, urban, rural)
- Standards of services and care
- Research information, contacts, techniques (medical, psychological, social)
- Legal information
- Local fund raising.

You can help the Campaign by mobilising the support of your Health Minister and WHO delegate to make the year 2000 a significant one for the millennium disorder of epilepsy. Please attend the Global Campaign seminar at the Prague Congress in September to learn more.

EH Reynolds,
Chairman, Global Campaign Executive Board
Another First

On 1 June 1999, the new IBE/ILAE Resource Centre will be opened - the first of its kind in the world. The notion that such a centre was needed was first articulated by Pete Engel, as part of his move to improve information-provision and communication for ILAE members. This has been a leading theme of his presidency, and other initiatives to this end include the expansion of Epigraph and the inauguration of Epilepsy Digest a new membership database and the new ILAE website (to be featured in the next issue of Epigraph).

The International Resource centre intends to collect ILAE and IBE information materials from all Chapters around the world. The collection will be catalogued and evaluated and the index will be available to all members, probably via the World Wide Web. The collection will comprise a broad range of material, which might include any of the following:

- Fact sheets
- Pamphlets
- Booklets and books
- Guidelines
- Posters
- Videos
- Material relating to audit
- Material dealing with standards/models of good practice
- Details of regular academic courses for doctors or the paramedical disciplines.

The Centre would like to have any material that originates from ILAE/IBE Chapters or members. The items need not necessarily have been produced under the auspices of the ILAE or IBE, but ILAE members should have had some involvement and the material should be relevant to epilepsy. The material will be evaluated by the Centre’s team and where appropriate archived. A computerised database has been installed and the collection will be categorised and indexed, and contact addresses for each item listed. This index will be available to ILAE and IBE members around the world. The collection should, over time, become a valuable resource, encouraging higher quality national materials and be a stimulus towards the worldwide integration of ILAE knowledge and information.

The collection of material has already begun, with contributions from IBE chapters and also the move of the IBE video collection (previously held in Breda). Accompanying this issue of Epigraph is a flyer inviting members to submit items for the collection. Dear reader, if you have any items of potential relevance for the collection, please do send it to Ian Mothersill at the Resource Centre. With your co-operation this will become a truly comprehensive and complete collection of information resource, and a tribute to the International Epilepsy Movement.

Sybille Reid and Ian Mottershill - Swiss Epilepsy Clinic

The Centre is based at the Swiss Epilepsy Centre in Zurich using rooms kindly donated by Schweizerische Epilepsie-Klinik. The project has been co-ordinated by a joint IBE and ILAE team (Judy Cochrane, Sybille Reid, Ian Mothersill and myself) and the Resource Centre is run by Drs Ian Mothersill and Sybille Reid, both of whom work at the Swiss Epilepsy Centre, and are devoting enormous time and energy to the project. An administrative officer is soon to be appointed and he or she will act as a contact person for all enquiries and contributions.

Simon Shorvon,
Co-Editor

Swiss Epilepsy Centre
Marrakech hosted first Treatment Gap Workshop

Marrakech hosted the first workshop on the Treatment Gap in Epilepsy in early May 1999. This was long overdue and the ILAE Commission for the Developing World organised the meeting with the aim of examining and debating in detail issues relating to the Treatment Gap for epilepsy, particularly in the developing world. Participants discussed a range of topics, and identified possible strategies which, if implemented effectively, would help reduce the treatment gap.

The workshop was a truly international event with participants from Argentina, Brazil, Ethiopia, France, Georgia, The Netherlands, Hungary, India, Pakistan, Russia, Senegal, South Korea, Switzerland, Tanzania, the UK, the USA and Zimbabwe. One important feature of the workshop was that it involved non-clinical specialists such as sociologists and anthropologists with an interest in epilepsy, specialists from other fields such as endocrinology (there is also a huge treatment gap in diabetes, for instance), as well as epileptologists, neurologists, neurosurgeons and psychiatrists.

The Treatment Gap

Topics covered in the first day of the meeting included existing definitions of the treatment gap and its causes, the epidemiology and aetiology of epilepsy in the developing world, the choice of AEDs for developing countries, and the various measures that might be implemented to prevent new cases. Some topics provoked a great deal of discussion, particularly on the second day of the meeting. These included the issue of sustainability of epilepsy interventions, and the ethical implications of starting programmes where their continuation could not be guaranteed. The financing of epilepsy programmes at community, national and international levels was also debated, since financial (and resource) considerations determine the success or failure of programmes in the developing world. As always the choice of AEDs provoked heated debate, with once again no conclusion being reached. The role of non-governmental organisations (NGOs) and the private sector in providing epilepsy services was discussed, and it was agreed that further consideration on this point was necessary, given the limited capacity of governmental health services to provide care. The group was unanimous on the need to raise the priority of epilepsy as a public health issue, at both national and international levels. Strategies to achieve this were discussed. The meeting also reported on the treatment gap in other conditions such as diabetes and hypertension, and how the experience in these may help the efforts to close the gap in epilepsy.

The main outcome of the workshop was a definition of the treatment gap for epilepsy. Treatment gap was defined as “the difference between the number of people with active epilepsy and the number whose seizures are being appropriately treated in a given population at a given point in time, expressed as a percentage”. This is not a final and binding definition, although the group felt that it incorporated all relevant aspects. The other main outcome was recognition of the various “new” issues, which will provide scope for future research and debate.

A more detailed report of the workshop will appear in Epilepsia and Epilepsia Digest at a later date. Epigraph will be publishing a summary report of the workshop in its next issue. It is reassuring to note that many of the issues discussed at the workshop were similar in scope to those flagged by our roving correspondents. A report on the subject, based on our roving correspondents’ accounts and insights, can be seen on pages 6 and 7.
Epilepsy Intervention in Developing Countries

Most people with epilepsy in developing countries are not receiving drug treatment. This treatment gap is the major issue confronting patients and doctors alike in these countries. In 1989, the treatment gap in three developing countries was calculated (see box). This shows that only between 6%-20% of patients with epilepsy are at any one time receiving treatment, a situation which is probably similar in many other countries.

<table>
<thead>
<tr>
<th>Country</th>
<th>Estimated no. patients with epilepsy</th>
<th>Proportion of patients receiving treatment %</th>
<th>Treatment gap %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ecuador</td>
<td>55,000</td>
<td>20</td>
<td>80</td>
</tr>
<tr>
<td>Pakistan</td>
<td>450,000</td>
<td>6</td>
<td>94</td>
</tr>
<tr>
<td>Philippines</td>
<td>270,000</td>
<td>6</td>
<td>94</td>
</tr>
</tbody>
</table>

There are many factors that interact in creating this gap and in providing care. Conditions across the developing world vary but common issues include the differing levels of resources, trained staff and infrastructure - and not least societal and governmental attitudes and priorities.

**Epigraph** hopes that debate on these issues will yield insights that help to improve services and bring epilepsy “out of the shadows”. To start the ball rolling we asked our roving correspondents across the world about epilepsy treatment in their respective countries and here are some of the points uncovered.

The cost of a drug and its availability are clearly most important factors. This problem can improve the role of NGOs only by co-operation of governments and drug companies, and negotiations over such issues as price, tax and distribution. Economic and political issues also influence the way that resources are allocated. Priority is often accorded to diseases with a high morbidity and mortality rate, and to the prevention of diseases such as measles and infective diarrhoea. Public health measures may help these conditions, but have little impact on epilepsy. It is in this context that epilepsy management has to be planned. Epilepsy management will often rely on the skills of community-based health workers, rather than qualified doctors in areas where the latter are in short supply. A reliable drug distribution network and basic system of record keeping are also needed, but often do not exist. Epilepsy services should not (and cannot) be implemented independently of the wider health services, and epilepsy is often below the line when it comes to prioritising health services.

**Too Clinical**

Whilst the scientific knowledge and technology to deal with the majority of cases of epilepsy exist, it appears that it is "non-medical" factors that determine success or failure. Since treatment involves long-term care, non-medical factors such as the cost of AEDs and seeking treatment, social and cultural attitudes, and the availability of and access to AEDs will all be of significance. Past projects have been criticised for taking "too clinical" an approach, and neglecting the socio-cultural factors that determine patient demand. Since treatment in most developing countries will be community-based, there is an even greater need to address such issues, involving and informing communities about what epilepsy is and is not, and building supportive environments. Some causes of epilepsy are preventable, such as those due to parasitic infestation. Where this is the case, support for public health measures (basic sanitation etc.) is encouraged. Given rapid urbanisation in developing countries, and limited health facilities to people in cities, consideration has to be made of how to provide care to slums and other less accessible areas. Geographical and climatic profiles are also important. Bangladesh, for example, is mostly underwater during the monsoon period, which makes the supply of drugs and access to health centres somewhat problematic.

**NGOs**

From our correspondents, it appears that the non-governmental sector often plays an important role. Whilst there is some criticism of the way that some private doctors and pharmacies operate, with profit as a driving force, other sections of the private sector can make useful contributions, particularly non-governmental organisations (NGOs). Most NGOs work with local communities and can identify local needs, resources and problems. They are better at getting messages across to communities in an appropriate and acceptable manner. NGOs might also be an effective way of distributing AEDs, since we hear from some correspondents that drug supply from government health services are sometimes notoriously unreliable.

It is clear that financing issues are extremely important and consideration needs to be given
to who is expected to pay for care. If it is patients, then demand and compliance rates are likely to be low as people allocate their money to areas of perceived priority - food, education and, in some countries, dowries. There is evidence of this occurring in countries that have introduced user fees for health services. Thus, given what we know about the tribulations of people with epilepsy, and the difficulties that they have with paying for care, there is a danger that they will continue to go untreated. The treatment gap, which we seek to close, will therefore remain.

**Cost of Drugs**

In the past, some states have provided AEDs without charge but, with the international political and economic turmoil of the last decade, this is no longer possible. The states of the former Soviet Union are interesting examples of what can happen when systems break down. People with epilepsy have gone in a relatively short period of time, from having full free care to no free care. Dr. Shpak, Epigraph’s correspondent in Russia, notes “in almost all regions Phenobarbitone, Phenytoin, Carbamazepine and Valproate should be given free of charge, but in reality there are many factors that make it impossible”. Dr. Gigineishvili, from Georgia, reports that the Ministry of Health Care is “no longer able even to refund the prices of conventional AEDs for patients”. The Dutch Red Cross helped by providing supplies of five AEDs for three years, but this valuable support has ended and “patients are faced with enormous difficulties”.

From Dr Sidiarto, our correspondent in Indonesia, we learn that government employees receive free health care but everyone else has to pay for it. This includes costs of AEDs. Supplies of AEDs are reliable only in urban areas, although this is unlikely in slum areas. The treatment gap in Indonesia is estimated to be between 75%-95%.

In Europe the costs of AEDs are often subsidised by governments. Thus, there is a perverse irony: those least able to pay for care (in developing countries) are expected to pay costs in full, while those in more developed countries have treatment subsidised or provided free.

**Sustainability**

The issue of sustainability has also arisen. Sustainability is the maintenance of an intervention that treats people with epilepsy successfully in the long term. Given the nature of AED regimens (where non-compliance can have severe complications), epilepsy interventions need at the very least to identify cases and guarantee reliable supplies of cheap, effective AEDs. Securing support for programmes from governments, NGOs and communities without being able to ensure AED availability and continuity may be counter productive. We cannot promise care and then fail to deliver it. This has already happened with many projects around the world, and has bred cynicism about donor-led programmes.

The ILAE/IBE/WHO Global Campaign is establishing demonstration programmes in some developing countries, which will hopefully serve as beacons of good practice for interventions in other countries. The Global Campaign and Epigraph welcome input from readers that might assist these programmes. The eventual goal is to reduce the treatment gap and bring epilepsy “out of the shadows”.

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Medical services are difficult to provide in remote areas
Archives Take Shape

To archive all the material from my period of presidency, I had the help of a document archivist, and the material was rearranged and stored in 135 boxes, taking about 15 metres of shelf space. The material was divided into obvious categories:

“Executive Meetings, General Assemblies and Council Meetings, Joint ILAE and IBE Executive Meetings, Chapters, Commissions, Symposia and Congresses, Workshops. Epilepsia and Epilepsy International News, World Health Organisation, and Constitution and By-Laws.”

The archivist was also able to develop a retrieval system, based on the package “Square-note”. Some of the files are incomplete, eg. those concerning commissions that often consisted of just a final report.

Where archives had been saved by a members of the commission, the files were more extensive, containing minutes and correspondance.

The success of an archive depends, to a great extent, on the Secretary-General. However, office archives are often structured differently from historical ones, so the latter need to be maintained by someone with expertise in that area. There is a proposal that the upkeep of the historical archives should be allocated to a museum for the history of epileptology. The feasibility of such an institution is currently being investigated.

Fortunately for the ILAE, other sources have been used to trace its history. At the inaugural meeting of the ILAE on Monday 29th August 1909, Donath and Muskens offered the use of the international journal Epilepsia as an official organ for communication with ILAE’s membership, and this has continued to date.

In 1994, a young Georgian medical doctor, Nathalie Goletiani, worked for a period at the archivist’s office, extracting a history of the ILAE from Epilepsia. This was first published as an internal report to the ILAE executive and has recently been published in Japanese by Dr. Yutaka Fukushima. As we wish to evolve the archives into a museum for the history of epileptology, any member of an ILAE Chapter who possesses material of historical interest and is willing to make it available to the community, is kindly invited to send this material to either the present archivist or the office of the Secretary-General.

Harry Meinardi
Leiden, March 1999

European Epilepsy Services Inventory

The Commission on European Affairs is engaged in the production of a European White Paper on Epilepsy. This will be a public health statement appropriate to European countries with ILAE/IBE Chapters.

As part of this work, a survey of the provision of epilepsy care will be conducted for each European country. The aim of the survey is to describe how basic epilepsy care is provided across Europe, but also to give an idea of the prevalence of highly specialised multidisciplinary epilepsy teams and to get an idea of the main problem areas related to epilepsy care in different countries. It is planned that the data from the European Epilepsy Services Inventory will be included as a supplement to the European White Paper on Epilepsy.

The European Epilepsy Services Inventory will be distributed early in the summer of 1999 to all the European Chapters. In order to be informative on basic aspects of the state of epilepsy care in Europe, it is important that there is a high response rate. We therefore sincerely hope for a positive response from all European Chapters of ILAE.

For the Commission on European Affairs, Kristina Malmgren, MD, PhD Dept. of Neurology Institute of Clinical Neuroscience Sahlgrenska, University Hospital S-413 45 Gottenburg, SWEDEN.
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International Merritt-Putnam Research/ Clinical Training Fellowship

The International League Against Epilepsy announces that applications for the International Merritt-Putnam Research/Clinical Training Fellowship are now being accepted. The Fellowship, made possible through an unrestricted educational grant from Parke-Davis, is awarded every two years and carries a stipend of $40,000. The Fellowship is designed for physicians outside North America who seek to develop expertise in clinical research, advanced diagnostic and therapeutic methodology, and professional education. The Fellowship offers qualified individuals the opportunity to pursue these goals through a two-year training and research experience at an established epilepsy centre.

Research projects may be in any aspect of epilepsy but should focus on epilepsy as a human disorder. Clinical studies in humans are encouraged. Proposals must include substantial training components in clinical research and advanced clinical management. Applicants must be physicians outside the US and Canada who have completed training in neurology, neurosurgery, internal medicine, paediatrics, or psychiatry. Deadline for receipt of applications is 15 January, 2000. For further information and application forms, contact Professor Peter Wolf, Secretary-General, ILAE Executive Office, Epilepsie-Zentrum Bethel, Maraweg 21, 33617 Bielefeld, Germany. Fax: +49 521 144 4637.
1999 AES
Annual Meeting

December 3 - 8, 1999

Location: DISNEY’S CORONADO SPRINGS Resort, Lake Buena Vista, Florida

The American Epilepsy Society is accredited by the Accreditation Council for Continuing Medical Education (ACCME) to sponsor continuing medical education for physicians. The Exhibit Hall is an integral part of the learning experience. Annual Meeting participants have an opportunity to learn about the latest in pharmaceuticals, publications, scientific equipment and technology relevant to the field of epilepsy.

The American Epilepsy Society has adopted and approved guidelines for industry-sponsored scientific exhibits at the Annual Meeting. Scientific exhibits differ from traditional poster presentations in that a broader range of material can be presented as a collection of topics, such as thematic presentation of one aspect of drug development.

The entire conference brochure and registration form may also be accessed on the AES Web site at www.aesnet.org. Reduced fee registration deadline is 1 November, 1999 and advance registration deadline is 15 November, 1999. After 15 November, you may register on site.

Preliminary Schedule

Friday 3 December
• Nurses’ Epilepsy Clinic
• Evening - Satellite Symposia

Saturday 4 December
• Merritt-Putnam Symposium
• Evening - Satellite Symposia

Sunday 5 December
• AES Annual Course
• AES Investigators’ Workshop

Monday 6 December
• Presidential Symposium
• Exhibits Open
• Poster Sessions
• Epilepsy Research Awards Luncheon
• Platform Sessions
• Evening - AES Antiepileptic Therapy Symposium

Tuesday 7 December
• Symposium II
• Poster Sessions
• Lennox Lecture
• Participatory Roundtables
• Special Interest Group Meetings
• Platform Sessions
• Evening - Satellite Symposia

Wednesday 8 December
• Symposium III
• Poster Sessions
• AES Annual Business Meeting
• Special Interest Group Meetings
• Platform Sessions
• Evening - Satellite Symposia

For further information:
American Epilepsy Society
342 North Main Street, West Hartford, CT 06117-2507
Tel: +860 586 7505 Fax: +860 586 7550
Email: kmurray@aesnet.org

The Annual Meeting consists of lectures, poster and platform presentations, satellite symposia and scientific exhibitions. This meeting offers members and non-members a forum for communication and disseminating current findings in the field of epilepsy and is an excellent opportunity for networking and sharing of ideas. The Annual Meeting is designed for the academic neuroscientist and neurologist, practising neurologist, neurosurgeon, internist, paediatrician, pharmacist, nurse, social worker and other allied professionals.
AUSTRALIA

New Antiepileptic Drug Trials Network
The Epilepsy Society of Australia has established an Antiepileptic Drug Trials Network to further enhance the excellent reputation of Australia as a major contributor to international multicentre AED trials. There are over 25 registered centres in the network, most with extensive experience in this area.

Chris Rowe
Email: crowe@tqehsmtp.tqeh.sa.gov.au

GREECE

Progress in development of epilepsy surgery programmes in Greece
Despite the extensive network of epilepsy care (300 private or hospital based neurologists; outpatient clinics in nine university departments of neurology as well as in the big regional hospitals), there is no centre yet offering a comprehensive epilepsy surgery programme. This lack of epilepsy surgery services has consequences on the quality of epilepsy care. With a national population of 11 million, there should theoretically be about 2,000 candidates for surgical treatment. However, only a very small proportion of these is actually operated on each year.

This issue was addressed recently at several national conferences: in March '98 at a symposium at the Aristotle University of Thessaloniki; in April '98 at a symposium in Athens organised by the University Dept. of Neurology - these two centres have made considerable progress towards establishing epilepsy surgery facilities.

Dr. V. Kimiskidis
Email: kimiskid@med.auth.gr

JAPAN

Monster seized Japanese children at the end of 1997
On the evening of 16 December 1997, many Japanese children suddenly suffered convulsions or physical discomforts while watching a children’s animated TV programme called “Pocket Monster”. This news ran all over the world. The Japanese Epilepsy Society (JES) sent out questionnaires to all members of the JES and received valid responses in a total of 279 cases examined directly by the members or their co-workers. In some 70% of these cases, the incident was the first experience. JES are now surveying the first year outcome. The results of these surveys will be presented at the 23rd International Epilepsy Congress in Prague.

Tadahiro Mihara
Email: shizuoka@szec.hosp.go.jp

SWEDEN

National Epilepsy Surgery Protocol
In Sweden a national multicentre prospective two-year follow-up study of all patients who underwent epilepsy surgery between 1995 and 1997 is being evaluated. The study is sponsored by the Swedish National Health Board and contains extensive patient data, including health-related quality of life outcome measures. Results will soon be available.

Eva Kamleit
Email: eva.kamleit@neurologi.uu.se

SAUDI ARABIA

Epilepsy Commissions launched to deal with all aspects of epilepsy in Saudi Arabia
The Saudi Chapter of Epilepsy has recently launched a series of commissions to deal with all aspects of epilepsy in Saudi Arabia. These new Commissions are named: Education, Classification and Terminology, Epidemiology and Prognosis, Antiepileptic Drugs, Neurosurgery, Patients Support, Epilepsy Genes.

Dr. Basim Yaqub
Email: 2185775@unicmail.com

SLOVAKIA

Slovak League publishes Epilepsy and Women guidebook
The Slovak League Against Epilepsy continues to carry out postgraduate activities. A recent collaboration with Mediform Glazo, the Slovak Neurological Society and the Postgraduate Institute has produced a third postgraduate publication entitled Epilepsy and Women. The book provides information on antiepileptic treatment in women, epilepsy and oral contraceptives, epilepsy and breast-feeding, epilepsy and pregnancy, and epilepsy and teratogenesis. These issues have all been researched and discussed with neurologists on a national-wide basis, and the authors are themselves all members of the SLAE. Previous books have covered therapeutic standards in epilepsy, and epileptic syndromes in infants.

Vladimir Donath
Email: vdonath@internet.sk

GERMANY

Epilepsy Awareness Day
As part of a national campaign to educate and raise public awareness about epilepsy, the LIGA has planned activities for the so-called “Tag der Epilepsie” - Epilepsy Awareness Day. The main theme this year is Education and Epilepsy.

Dr. Ingrid Tschorn
Email: ttx@neuro.mar.de

URUGUAY

Local Chapter's Educational Program continues
During 1999, the Uruguayan Chapter Against Epilepsy will coordinate its efforts with the official educational authorities in targeting school and high school teachers. In this way, teachers will themselves be educated about epilepsy within the Chapter’s existing educational programme.

Dr. Diana Yorio
Email: diayorio@mednet.org.uy

TURKEY

Web site launched
The Turkish Epilepsy Society has developed its own web site as a means of communicating information for doctors and members alike. The address is: www.members.noidps.com/~epilepsy/

The first Turkish epilepsy database has been put together by Dr. Mustafa Eras, including data about patients with epilepsy collected from ten centres since 1998. By the end of 1999, this programme will be used nationwide. The “EPIBASE” is to be presented at the 23rd IEC in Prague in September.

Candan Gurses
Email: cgurses@superonline.com

INDONESIA

PERPEI News...
PERPEI has begun conducting seminars on epilepsy to national high school children and teachers. In collaboration with the Department of Neurology at the University of Indonesia, a study on the possibility of secondary epilepsy being caused by neurocysticercosis has been conducted. A report on this preliminary study will be presented at the 23rd IEC Congress in Prague in September 1999.

A traditional drug trial with piperazine as an anticonvulsant is due to start in 1999.

Lily D. Sidiarto
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TUNISIA

TAAE working with national health services to fund incorporating for antiepileptic drugs
The efforts of the Tunisian Association Against Epilepsy are directed towards improving the quality of life of people with epilepsy and to supply hospitals with antiepileptic drugs. A multi-centre prospective study on the quality of life of children with epilepsy in Tunisia has been ongoing since February ’99, and the TAAE are working in close contact with the national health services to identify the need to include antiepileptic drugs within existing budgets.

From this year, 24 April has been designated as National Epilepsy Day in Tunisia.

Dr. Mohamed Frejd
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CONTRIBUTIONS

Have your say! Contributions to the Bulletin Board are welcome from any organisations or individuals with a ‘story to tell’. Please e-mail the Epigraph Office; epigraph@ion.ucl.ac.uk or write to Juliet Solomon at 6th Floor, Institute of Neurology, Queen Square, London WC1N 3BG. Contributions for the next issue of Epigraph, to be published in December, must be received by 29 October 1999.
Epilepsy 50 Years Ago

This occasional feature focuses on epilepsy-related publications of 50 years ago. In this edition, we thought that you might like to be reminded of four influential papers from 1949; these papers came from the stables of some of the epilepsy luminaries of the time and they give an idea of what people were working on then. We will leave the reader to form their own opinion as to their relevance to our present understanding and practice! Here are their abstracts:


“Taking essentially the electrographic evidence of a spike in the temporal region of the scalp as their base, the authors emphasise the fact that psychomotor seizures, when they are very minor, can be reduced to a physical aura which at first sight can be taken for an absence. The authors suggest clinical and electroencephalographic criteria that will allow the differentiation between idiopathic absences and temporal pseudo-absences.”


“EEGs of patients without brain injury were studied. Of 59 cases of petit mal, 37% were controlled by medication. The EEGs became normal in 72% and were improved in 23%. Thirteen patients were unimproved by medication. In this group, there was no EEG improvement. In 49 cases with other types of seizures, 33% were kept seizure free with medication. In only 31% of these the EEGs were normal. In general, clinical results and EEG improvement run a broadly parallel course. In 66% of the 108 periods of treatment, there was complete correlation. In 30%, clinical improvement was greater than electrical. The correlation between the two is best for the petit mal group.”


“Vocalisation without words was evoked by stimulation of the sensorimotor cortex in the region where lip and tongue movement are represented in both hemispheres. Arrest of speech was provoked by stimulation in much the same area bilaterally. This arrest appears to be due to interference with vocalisation or articulation. Arrest of speech was also produced by stimulation in the dominant hemisphere in extratemporal regions, a frontal region and a parietal region anterior to fissure of Sylvius. In these locations, arrest of speech appears to be due to interference with thought processes involved in the speech mechanism.”


“Random spike is the only electrical sign pathognomonic of a local epileptogenic lesion. Similar in form regardless of the cortical area from which recorded; those spikes if conducted to distant areas, may show temporal dispersion and appear as sharp waves. Clinical manifestations occur only when the random spike discharges begin to fire repetitively and attain a higher voltage. However, little obvious changes in the patient is observed if the repetitive firing is taking place in areas like the anterior frontal regions and portions of the temporal and parietal love. Changes in consciousness are due to a spread to subcortical structures. The epileptic cortical after-discharges can be maintained after the cortex is isolated from connections to subcortical structures, but bilateral synchronous rhythmic activity most probably has its pacemaker in the subcortex. “The clinical pattern of a seizure depends on the brain involved and not on the form of the EEG disturbance.”

Famous People with Epilepsy

This issue’s “famous person with epilepsy” is the noted French writer and thinker, Gustave Flaubert (1821-1880). His novels are characterised by vivid and life-like characters, and his most famous Madame Bovary (1856), “a poetically realistic assessment of a case of adultery in a village in Normandy” is considered by some to be the perfect French novel.

Flaubert had his first seizure in 1844, while training to be a lawyer. We know a great deal about his epilepsy from letters that he wrote to friends and colleagues, in which he described his experiences. In one particular letter, he says:

“It seems to me as if my consciousness, my very being, floundered like a ship in a stormy sea. But I held fast to my reason. It dominated everything, although I was besieged then and then beaten down... there was a terrifying tearing away of my soul from my body, but the thing that defines personality, the faculty of reason, held on until the very end. My mental life would desert me and my consciousness would disappear, as would any feeling of being alive. I am certain that I now know what it is like to die.”

Flaubert was convinced his epilepsy affected his work, making writing a tedious and even painful process. He lamented:

“You do not know what it is like to remain the whole day with one's head pressed against one's hands to squeeze a single word out of the brain.”

The “treatments” Flaubert underwent for his epilepsy included blood-letting and poultries, as well as “ferocious hydrotherapy”, infusions of lime and orange blossom tea, and dieting, which he described as “the spectre a thousand times worse than all the diseases of the world”. He also used the anti-epileptic drugs of the day - bromide, mugwort, indigo, valerian and castor oil.

Despite his epilepsy, and the apparently harsh measures used to treat it, Flaubert was still able to produce a remarkable body of work, including Salammbô (1862), The Temptation of St Anthony (1874) and Three Tales (1877).

His death in 1880 was not a result of his epilepsy, although attempts to link the two have been made by some. Whatever the cause of his death, Flaubert today remains one of the world’s great literary figures, who refused to let his epilepsy get the better of him. His work is testament to this.

Sources:
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. Kindly provide date, venue, subject and contact details including contact person, address, telephone/fax numbers & email address. Please forward this information to the Epigraph office (details at end).

23rd International Epilepsy Congress, Prague, Czech Republic, 12-17 September 1999

Topics of the congress are: "Epileptic seizures and syndromes in childhood"; "Epileptic surgery"; "Plasticity and epilepsy"; "Fetal, interictal and semieclastic events"; "Living with epilepsy"; "Epilepsy and work"; "Epilepsy and adolescence". Contact: Congress Secretariat: Guarant Ltd/23rd IEC, Opletalova 15, 110 00 Prague 1, Czech Republic. Tel: +420 2 24 21 07 35/06 50. Fax: +420 2 24 21 21 03. Email: IEC23@guarant.cz

Workshop on Prophylactic Epilepsy Driving Restrictions, Prague (as above)

This workshop is planned to run during the 23rd IEC and will deal with "epilepsy risks following trauma", "vascular accidents and infections". For participation please contact: Dr. John Kirker, Chairperson, IBE Commission on Driving Regulations, c/o International Bureau for Epilepsy, 253 Cramlin Road, Dublin 12, Ireland. Fax: +353 1 455 46 48. Email: tiec@indigo.ie

1st Annual Meeting of Saudi Chapter of Epilepsy, Riyadh, Kingdom of Saudi Arabia, 5 October 1999; and Epilepsy Workshop, 5-7 October 1999

Both events will be held at the Riyadh Armed Forces Hospital. Main topics of the annual meeting include epidemiology, classification, genetics, epilepsy surgery, neuroimaging and antiepileptic drugs. For further information please contact: Miss Claire Rivers, Secretariat, Saudi Chapter of Epilepsy, Riyadh Armed Forces Hospital, P.O. Box 253 Crumlin Road, Dublin 12, Ireland. Fax: +353 1 455 46 48. Email: tiec@indigo.ie

Annual Scientific Meeting of the Epilepsy Society of Australia, Adelaide, South Australia, 18-20 November 1999

The venue for this meeting is the Adelaide Hilton International, Victoria Square, Adelaide. Keynote speakers will be Prof. Richard Matson, Yale University and Dr. David Teimian, University of Medicine and Dentistry of New Jersey. Further information can be obtained from: Elizabeth Eaton, Director/Conference Manager, Festival City Conventions Pty Ltd, PO. Box 949, Kent Town SA 5071, Australia. Tel: +61 8 8363 1307. Fax: +61 8 8363 1604. Email: fceaton@usemail.com.au

3rd International Santa Margherita Ligure Symposium, 2nd Regional Meeting of the Mediterranean Stroke Society, Genoa, Italy, 25-26 November 1999

The theme of this meeting is: New Therapeutic Strategies in Ischemic Stroke including discussion on "From the Stroke Unit to rehabilitation: Medical problems and Policy Guidelines". The meeting is jointly organised by the San Martino Hospital, Genoa, the University "La Sapienza", Rome and the Tel Aviv Medical Centre, Tel Aviv, and co-sponsored by WHO, for further information please contact: Dr. A. Seneghini, Stroke Unit, Dept. of Neurology, San Martino Hospital, Largo R. Benzi, 10-16132 Genoa, Italy. Tel: +39 010 555 3320/2542. Fax: +39 010 555 660/36762. Email: ictus_neuro@smartino.ge.it

53rd Annual Meeting of the American Epilepsy Society, Orlando, Florida, 3-8 December 1999

This meeting will be held at the Disney Coronado Springs Resort in Orlando, Florida. For further information please contact: Karen Murray. Tel: +860 586 7505. Fax: +860 586 7550. Email: info@aesnet.org

5th Eilat Conference on New Antiepileptic Drugs (Eilat V), Eilat, Israel, 25-28 June 2000

The Danish Neurological Society celebrates its 100 year anniversary, and the EFNS 2000 Congress will be held at Copenhagen's Bella Centre. Main topics are Stroke; Epilepsy: Neuropathy, Movement Disorders; Headache; Cost-effectiveness of Treatment in Neurology; Dementia; MS and Addiction-related neurological disorders. There will also be teaching courses and special lectures. For further information please contact: EFNS 2000, c/o DIS Congress Service Copenhagen A/S, Herlev Ringvej 2C, DK-2730 Herlev, Denmark. Tel: +45 4492 4492. Fax: +45 4492 5050. Email: efns@discongress.com

3rd Congress of Asian Oceanian Epilepsy Organisation (AOED), New Delhi, India, 11-13 November 2000

For further information please contact: Dr. Sarith Jain, Secretary General, Dept. of Neurology, Neurosciences Centre, All India Institute of Medical Sciences, New Delhi-110 029. Tel: +91 11 659 4210/656 9007. Fax: +91 11 652 1086/686 2663. Email: satjian55@hotmail.com

4th European Congress of Epileptology, Florence, Italy, 7-12 October 2000

This congress will be held at the Forteza Da Basso. Main topics include: "Anatomo-Electronclinical Aspects of Fronital Lobe Seizures"; "Symptomatic Epilepsies"; "What can be learned from Human Tissue Study"; "Relationship between Presurgical Evaluation Strategy and Surgical Results"; "Adverse Effects of AEDs". Contact: Maura Stella, PTS Congress, Via Tevere 20, 00197 Rome. Tel: +39 06 85 35 55 59. Fax: +39 06 85 35 60 60. Email: pncong@tin.it

II Latinoamerican Epilepsy Congress, Santiago, Chile, 8-10 September 2000

This is the First Latin American Epilepsy Congress committed to the ILAE/WHO/IBE slogan “Bringing Epilepsy Out Of The Shadows”. The meeting will be attended by Dr. Jerome Engel (President/ILAE) and Dr. Richard Holmes (President/IBE). For further information please contact: Dr. Manuel Campos, Epilepsia 2000, Pasaje Lo Gallo 1787, Vitacura, Santiago, Chile. Tel: +56 2 232 9347. Fax: +56 2 229 6731. Email: mcampos@med.puc.cl

5th Congress of the European Federation of Neurological Societies (EFNS 2000) Copenhagen, Denmark, 14-18 October 2000

The Danish Neurological Society celebrates its 100 year anniversary, and the EFNS 2000 Congress will be held at Copenhagen's Bella Centre. Main topics are Stroke; Epilepsy: Neuropathy, Movement Disorders; Headache; Cost-effectiveness of Treatment in Neurology; Dementia; MS and Addiction-related neurological disorders. There will also be teaching courses and special lectures. For further information please contact: EFNS 2000, c/o DIS Congress Service Copenhagen A/S, Herlev Ringvej 2C, DK-2730 Herlev, Denmark. Tel: +45 4492 4492. Fax: +45 4492 5050. Email: efns@discongress.com


The theme of this meeting is: New Therapeutic Strategies in Ischemic Stroke including discussion on "From the Stroke Unit to Rehabilitation: Medical Problems and Policy Guidelines". The meeting is jointly organised by the San Martino Hospital, Genoa, the University "La Sapienza", Rome and the Tel Aviv Medical Centre, Tel Aviv, and co-sponsored by WHO, for further information please contact: Prof. A. Seneghini, Stroke Unit, Dept. of Neurology, San Martino Hospital, Largo R. Benzi, 10-16132 Genoa, Italy. Tel: +39 010 555 3320/2542. Fax: +39 010 555 660/36762. Email: ictus_neuro@smartino.ge.it

4th Pan-American Congress of Neurology, Cartagena de Indias, Colombia, 9-15 October 1999

For further information contact: Dr. G. Pradilla, Av. 15 no. 106-50 Of. 505, Santafe de Bogota, DC, Colombia. Tel: +571 612 7115. Fax: +571 619 1807. Email: panamcol@uis.edu.co

50th Anniversary National Annual Meeting of French Chapter of ILAE, Paris, 23-26 October 1999

This meeting marks the 50th anniversary of the French Chapter and is called "Journées Francaises de l'Epilepsie (JFE99). The meeting's theme is: Prevention of Epilepsies. For further information please contact: Julie Boursier, Paediatric Neurology Department, Hospital Robert Debret, 75019 Paris. Fax: +33 1 40 03 47 74. Email: www.lfe-epilepsies.org