

# EpigrapM

THE NEWSLETTER OF THE INTERNATIONAL LEAGUE AGAINST EPILEPSY

ISSUE 1 2000

## Editorial

*"For all that moveth doth  
in change delight"*

It is commonplace that, every-so-often, organisations have the urge to change themselves. This navel-gazing is postulated to be a healthy response to an evolving world and, as many have found to their cost, to be unchanging is to ossify. It is in this spirit that the ILAE is, in Basel in April this year, to embark on its first strategic review (horrible late 20th Century jargon, but strangely appropriate). In this edition of *EpigrapM*, the ILAE President, Pete Engel, outlines his contribution to this review. In future editions, the results of this exercise, which involves wide consultation, will be published. From these, readers will be able to judge the health and the youthful vigour of the League. For those whose favourite gear-change is reverse, our Past President Ted Reynolds contributes an article about epilepsy in the past 100 years and tells us what has and has not changed. Finally, we print a piece on page 5 concerned with educational change. The article by Peter Wolf, our Secretary General, outlines the activities of EUREPA; the new organisation associated with the League which aims to change the way epilepsy education is conducted throughout Europe.

Simon Shorvon, Co-Editor

## President's Message

# Questions of Identity

**The International League against Epilepsy is an organisation of chapters, as opposed to an organization of members. As such, it has been faced periodically with questions of identity. To what extent does the League exist solely to support its chapters, to what extent should it carry out independent functions that could conceivably conflict with those of its chapters, to what extent should it attempt to directly serve the individual members of its chapters, and to what extent should it reach out to countries, and individuals, that do not have chapters?**

In recent years, the financial resources of the League have grown substantially, due in part to the tremendous progressive increase in attendance at the International Epilepsy Congresses, and in part to the growing importance of our journal, *Epilepsia*. As a result, the League has been able to undertake many new projects, which have gradually transformed it into a much more professional and pro-active organisation. For instance, in 1997, the League retained a professional association manager (Peter Berry) to establish our formal Financial Office; last year, together with the International Bureau for Epilepsy, it hired its own professional meeting planner, Richard Holmes; a professional journal consultant, Dr. Morna Conway, is guiding our current efforts to negotiate a new contract for the publication of *Epilepsia*; and we have more and more frequently required the services of a professional international association advisor (Dr. Walter Schaw), and a lawyer (Art Herold), to help us work through the administrative, legal, and at times ethical, dilemmas that arise out of our expanding activities, which now often involve formal collaborations or contractual arrangements with other organizations.

On April 15, in Basel, the ILAE will hold its first formal strategic planning meeting, under the professional guidance of Dr. Walter Schaw. This meeting will include members



Basel, Switzerland

of the Executive Committee, chairs of commissions, and other selected key participants in League activities. It is designed to assess our progress over the past one-and-a-half executive terms, and set an agenda for the future. Clearly the League has played an important role in co-ordinating the international epilepsy community through the International and Regional Congresses, and though the publication of guidelines and classifications.

At this time, however, it will be important to determine how much more active the League should be in initiating global projects and to identify mechanisms by which clinical, scientific, educational, and political objectives might be achieved at an international level that would support the work of its chapters at a national level,

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## President's Message *continued*

without compromising chapter integrity and independence. The League carries out its primary functions through its commissions, as well as special task forces and working groups, appointed by the President with the advice and consent of the Executive Committee. Chapter representation on these commissions, task forces, and working groups is essential for coordinating League activities with those of its chapters. It is therefore important that members of our chapters play an active role in these League affairs. In particular, the new concept of regional commissions ensures that all chapters have formal input into League activities via the important roles these commissions play in the administrative decision-making process of the League. Although we are proud of the fact that the current Executive Committee represents a broad geographic constituency, and appointments of all official League bodies are made with geographical diversity in mind, we are aware of the fact that larger and better-established chapters traditionally monopolize the leadership of the League. Consequently, we continue to strive to increase involvement of our newer and smaller chapters in the League administrative structure. It may ultimately be necessary, however, to create more formal ways to accomplish this.

### Objectives

**To what extent does the League exist solely to support its chapters?** Although in the past many considered this to be the primary justification for the ILAE, the objectives set forth in the constitution are much more global in scope: 1) the advancement and dissemination throughout the world of knowledge concerning the epilepsies; 2) the encouragement of research concerning the epilepsies; 3) the promotion of prevention, diagnosis, treatment, advocacy, and care for all persons suffering from these disorders; and 4) the improvement of education and training in the field of the epilepsies. It might be argued, therefore, that the chapters are obligated to aid the League in carrying out these international objectives, as much as the League is obligated to help each chapter carry out its objectives within its own national boundaries. Consequently, the League has a duty to encourage its chapters to practice good global citizenship by contributing to the League's efforts to carry out its international agenda. To a certain extent, these goals are furthered by establishing new national chapters; however, the ILAE, by its very designation, has a commitment to all countries, not just those

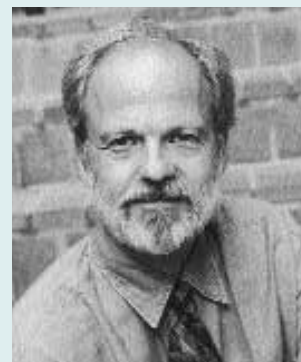
that currently have, or wish to develop, chapters.

### Chapters

**To what extent should the League carry out independent functions that could conceivably conflict with those of its chapters?** The ILAE, often in concert with its lay sister organization, the International Bureau for Epilepsy, has undertaken a number of independent projects in recent years, including: the Global Campaign against Epilepsy, in partnership with the World Health Organization, which is now to be elevated to cabinet level, the highest priority within the WHO; the Resource Center, organized in collaboration with the Swiss Epilepsy Center in Zurich; and our new website, which we hope to launch as a comprehensive epilepsy portal site in the near future. Each of these major projects directly addresses the objectives of the League; however, they also have potential to compete with activities currently underway, or planned, by some of our individual chapters. It is essential that the League Executive Committee continue to be sensitive to these potential conflicts, regularly inform chapters of its activities, and invite chapters to voice their concerns. These, and future projects like them, will succeed only to the extent that we are able to coordinate our efforts with those of our chapters and complement, rather than compete with, individual chapter initiatives.

### Individuals

**To what extent should the League attempt to directly serve the individual members of its chapters?** In the past, the League Executive Committee was concerned that chapters may not wish the League to become directly involved with its membership. At the beginning of this executive term, I addressed this issue with each chapter before we agreed to invoice members directly for discount subscriptions to *Epilepsia*. There was no objection to the League contacting members directly to make them aware of such benefits, and to process certain requests, such as discount subscriptions, which now include several other epilepsy journals as well. The League also communicates directly with its membership through this newsletter, which has been very well received. After a more recent survey of chapter opinions, there has been an enthusiastically positive response on the part of most chapters to share their membership lists, at least with other chapters, via a password-protected membership directory page on our website, which is



Jerome Engel

intended to enhance interactions among members of different chapters. What the League Executive does not do, and should never do in the future, is contact individual members to influence their opinions on issues, or act on direct input from individual members on issues, that are the prerogative, or would compromise internal governance, of their chapter.

### Extending the work

**To what extent should the League reach out to countries, and individuals, that do not have chapters?** The objectives of the League, noted previously, could not be pursued without attention to areas of the world where no chapters exist. Indeed, if the ILAE Executive Committee has a primary mandate to carry out independent activities that do not conflict with those of its chapters, then this would be to extend the work of the League to countries where no chapters exist. These are central goals of the Global Campaign against Epilepsy and the Regional Commissions. However, there currently is no regional commission for Africa, where sub-Saharan Africa has the greatest underserved population and the smallest number of ILAE chapters of any comparable area in the world. A major recent commitment of the League is to reach out to sub-Saharan Africa, not only to help create new chapters, but to advance and disseminate knowledge, encourage research, promote prevention, diagnosis, treatment, advocacy and care, and improve education and training, in the field of epilepsy, particularly in countries where there are no chapters, and are not likely to be chapters for many years to come. Just as the League exists in part to support the activities of its chapters, we hope that each of our chapters will consider these global objectives of the League to be part of their national agendas as well, and look forward to seeing an increasing enthusiasm on the part of our chapters to participate in the international activities of the League.

Jerome Engel Jnr  
President, ILAE



# A Century of Epilepsy

**Only at the turn of the last century did epilepsy begin to emerge from the dark shadows of superstition which were associated with it for the past four thousand years, for example, in the detailed accounts of epilepsy in Babylon. Supernatural theories of epilepsy at last began to give ground to the concept of a brain disorder under the influence of the newly developing discipline of neurology. Electrical theories of epilepsy had been developed and confirmed by Todd, Jackson, Hitzig and Ferrier. A remarkable new treatment in the form of bromides was increasingly utilised although then, as now, most people in the world with epilepsy received no effective treatment at all.**



Ted Reynolds

**H**umanitarian considerations had led to the establishment of caring and employment oriented 'colonies' in Europe and the USA. However, these more enlightened medical and social attitudes were still dominated by misconceptions of epilepsy as a mental disorder, perceived as very often leading to mental and intellectual deterioration based on exaggerated views of the influence of hereditary factors. Although much modified and diluted, such views are still perpetuated today by the WHO's misleading characterisation of epilepsy and neuroscience as a subspecialty of mental health.

## Discovery

The outstanding discovery of the first half of the 20th century was that of the electroencephalograph by Berger in the 1920s. This reinvigorated electrical concepts of epilepsy and especially since the Second World War led to the rapid growth of neurophysiology, to new animal models of experimental epilepsy and to new approaches to the diagnosis and treatment of epilepsy, including surgery. In the second half of the 20th century the surface EEG became the standard investigation in the diagnosis and classification of seizure disorders, but like all new discoveries, it has been much misused, overused or misinterpreted, especially in inexperienced hands, which is all too common. Much can be done in diagnosing and treating epilepsy in developing countries without an EEG. In more developed countries the trend in recent years has been towards more sophisticated, more focused and more prolonged recordings, especially video telemetry, using multiple, specialised electrode placements, sometimes in

depth, in specialised centres addressing more specific, intractable problems.

The rapid development of structural and functional imaging techniques in the last thirty years, including CT, MRI, SPECT and PET, has had a major impact on the investigation and understanding of



Epilepsy Tablet in the British Museum

epilepsy. Brain lesions, often subtle, are now found in significantly higher numbers of epileptic patients than hitherto. Newly discovered pathologies, such as cortical migration disorders, are opening up new avenues of exploring epileptogenesis and its relationship with brain development. These new imaging techniques, in combination with modern

electrophysiological methods, have shed new light on the complex relationship between structure and function in the brain as it applies to the diagnosis, classification, treatment (especially surgical) and prognosis of seizure disorders.

## Distinct syndromes

In the last fifty years the brain sciences have opened up many tantalising possible mechanisms of epileptogenesis in the mammalian brain, including neurotransmitter, ion-channel, membrane, nucleoprotein, hormonal and other metabolic processes. Very little of this has yet penetrated clinical practice. However, in recent years careful clinical, developmental, genetic, neurophysiological, neuroimaging and prognostic studies have delineated several distinct epilepsy syndromes of childhood and adolescence. The new molecular biology and genetics are expected to advance our understanding of the aetiologies and more specific treatments of these syndromes in the 21st century. The recent growth in paediatric epileptology has been matched to some extent in the developed world by the rising incidence of epilepsy in old age as people in the West live longer; and also by increasing recognition of the needs of special groups such as those with learning disorders, whose risk of epilepsy increases with the degree of intellectual impairment.

## New drugs

In the first half of the 20th century two new anti-epileptic drugs were discovered, phenobarbitone (1912) and phenytoin (1938), which remain today the most widely used anti-epileptic drugs in the world, largely because of their cheapness.

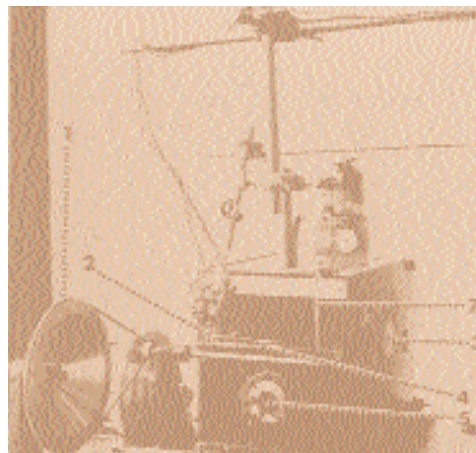
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The period from the 1950s to the 1970s saw a rapid growth in newly available drugs, of which carbamazepine and sodium valproate have been most enduring. All these new and older drugs exacerbated the centuries-old philosophy of polytherapy for epilepsy, with increasing problems of chronic toxicity, especially of a cognitive and behavioural kind. This was followed in the 1970s and 1980s by a more rational approach to anti-epileptic therapy, facilitated by newly developed blood drug monitoring techniques. It gradually dawned that the majority of patients with newly diagnosed epilepsy could be controlled by a single drug and that there were limits to the role of polytherapy, which could even occasionally exacerbate seizures. Some of these gains were lost in the 1990s with the rapid marketing of several new anti-epileptic drugs, for which monitoring was abandoned. Polytherapy is on the rise again and physicians and patients alike are somewhat bewildered by the possible choices and the wide-ranging costs of drugs. Nevertheless, standards of clinical evaluation of all treatments enormously improved in the last half of the 20th century. Out of some of these long-term trials, together with epidemiological studies, has emerged a more optimistic view of prognosis of most seizure disorders. Factors that lead to intractability in the minority have been clarified, but opinions still differ as to whether early medical treatment influences long-term outcome.

### Alternative approaches

Despite great progress as in neuro-chemistry and neuropharmacology, the mechanism of action of our anti-epileptic drugs remains far from clear, with the possible exception of vigabatrin. In the absence of a clearer understanding of the neurochemical mechanisms underlying human epilepsy, we lack cures for epilepsy except possibly surgery in a small minority of cases. The need for long-term pharmacological treatment with all its disadvantages has focused attention recently on alternative neurophysiological approaches such as biofeedback and stimulation techniques, the role of which will be clarified in this century.

The second half of the 20th century also saw the increasing application of surgical techniques, especially resective temporal lobe surgery, for newly recognised pathologies such as mesial



EEG, as it was!

temporal sclerosis, in specialised centres. However, even in developed countries, resective and functional neurosurgery are available only to a minority of the minority of patients who might potentially benefit, due to a lack of human and financial resources.

### Attitudes

Public attitudes to epilepsy, although improving slowly, have not kept pace with the rapid growth in our scientific and clinical understanding and treatment of the disorder. There is much truth in Rajendra Kale's view that 'the history of

epilepsy can be summarised as four thousand years of ignorance, superstition and history of stigma, followed by a hundred years of knowledge, superstition and stigma' (British Medical Journal, 8 July, 1997). Epidemiological studies indicate that over one hundred million people in the world will have epilepsy at some stage in their lives, usually in childhood or adolescence, the vast majority of whom will receive no, or at best, inadequate treatment and care. It is scandalous that the 'treatment gap' in most of the developing world (which accounts for 85 percent of people with epilepsy) varies between 60 and 90 percent, largely due to social reasons. Only as the last century ended was the tragic complication of SUDEP, and the fourfold increase in the death rate among young people with epilepsy, widely recognised, although still not understood or prevented.

### Universal disorder

The International League Against Epilepsy (ILAE) was founded in 1909. After two interruptions due to world wars, it grew steadily in the second half of the 20th century and in 1962 helped to found the International Bureau for Epilepsy (IBE). As the 20th century ended, both had grown into truly global organisations and joined forces with the World Health Organisation in a Global Campaign to bring epilepsy 'out of the shadows'. Epilepsy is perhaps the most universal of all medical disorders with no age, race, social class or geographical boundaries, yet it remains hidden and neglected by nearly all governments and departments of health.

I feel privileged to have been involved in the last forty years of epilepsy, during which there has been more progress in our understanding and treatment of the disorder than at any period in the last four thousand years. Although we are still only in the foothills, it augurs well for the mountain climbing to come in this new millennium.

**E. H. Reynolds, Past President, ILAE**



Albert Speer would have been proud of this advert!

# Eurepa has Impact

**Eurepa Course has had an impact on Epileptological Education in Five Eastern European Countries. The Academy's first trainer course consisted of two parts: a one-week seminar on November 18-22, 1998, in Budapest, and a one-day workshop on September 17, 1999 at the 23rd International Epilepsy Congress in Prague.**



**D**uring the Budapest seminar, a group of selected trainees from Central and Eastern European countries met with the members of the Executive Board of EUREPA for what turned out to be a common learning experience for junior and senior epileptologists. The seniors each gave an extensive lecture on a topic which would be typical for an educational course in epileptology. The juniors each contributed one short talk on a subject of their own choice, and a case presentation. There were group discussions which gave equal weight to the epileptological contents of the talks, and to the didactic aspects of the various types of presentations, course organisation and evaluation.

At the end of what developed into an intense and highly rewarding and communicative group experience, the "trainees" were given the task of organising, at home, some educational activity of their own choice, and report back at a workshop in Prague.

## Stunning

The reports given at the Prague workshop were stunning and revealed, far beyond expectation, that the course had had a major impact, of one kind or the other, on each of the countries represented. To highlight some of these:

- in Armenia, the Ministry of Health has added "epileptologist" and "clinical neurophysiologist" to the category of narrow specialties. A comprehensive epilepsy course programme has been installed as part of the curriculum for specialisation in neurology. For the students of the Armenian State Medical University, an extended epilepsy teaching programme has been established. The first Annual Postgraduate Review Course "Basic & Clinical Epileptology" was started in January 1999. Under the umbrella of the Armenian League Chapter ANLAE, an organisation for patients and their relatives is being established whose aims include education;
- in Estonia, education in epilepsy has been included in both pregraduate and postgraduate teaching programmes for general practitioners, psychiatrists and

epilepsy specialists. The Centre of Postgraduate Training of the Medical Faculty gives credit points for these activities. An educational WebSite is in preparation;

- in Georgia, a 4-day course on epilepsy has been implemented in the last ("prediploma") year of primary medical education. Seminars on epilepsy have been given for neurologists and for gynecologists and obstetricians;
- in Lithuania, 2-week courses in paediatric epileptology, and in clinical electrophysiology (for neurologists and neuro-pediatricians, with special emphasis on epilepsy) for groups of 4-8 participants, with credit points given, have been developed in cooperation with the Kaunas Medical University and the Health Ministry. Education on epilepsy has been included in the postgraduate neurological training programme for general practitioners, and programmes for further education of residents, nurses and paramedics are under development. A grant from the Soros Foundation is mainly used for education of medical staff, patients and families including publications, workshops, seminars, and training in well-known epilepsy centres abroad. The "Standards of Appropriate Epilepsy Care Across Europe" were extensively discussed at meetings with neurologists and psychiatrists. Two television programmes for people with epilepsy were broadcast;



Budapest - the location for the Eurepa one-week seminar

- in Russia, epileptological educational lectures on EUREPA level became part of educational activities of the All-Russian Neurological Society at various places, and small-group educational courses in pediatric epileptology have been introduced. The lectures particularly emphasized the "Standards of Appropriate Epilepsy Care Across Europe" of the ILAE European Commission, which prompted extensive debates. Participants of these activities have started to found epilepsy units in neurological centres. Several educational publications on epilepsy have appeared in print.

## Improvement of knowledge

Although the existing educational systems for specialisation differ, the participants had found it necessary in all countries first to concentrate on the improvement of knowledge about epilepsy at the primary (physicians in general) and secondary (neurologists, pediatricians and psychiatrists) level before developing education at the tertiary level. For the latter, the development of "educational centres" has been proposed as a next step and this is fully in line with the Academy's intention to develop an educational network across Europe with "knots" where educational modules can be presented, ideally in the local language.

All participants agreed that there is a great need for educational print and audiovisual materials of good quality. If these were available in English they would be willing to translate them if necessary.

To keep alive the impetus given by the Trainer Course, the participants made a strong plea for a follow-up programme and proposed two specific items:

- a visiting programme to leading European epilepsy centres in small groups of 3 - 5 participants, and
- regular meetings at the European Congresses of Epileptology.

At the end of the course, the participants received their Certificates as Trainers of the European Epilepsy Academy. With these, the trainers are entitled to organize EUREPA-certified educational courses as laid out in the rules for educational activities of the Academy.

**Prof. Dr. Peter Wolf, Chair, EUREPA**



# Famous People with Epilepsy



## Elizabeth Dade Jackson

Of all the 19th century neurologists few have meant more to epileptology than John Hughlings Jackson. Amongst his great contributions were the first modern descriptions of focal motor seizures, arising in the central neocortex, which now carry his name (the so-called Jacksonian seizures). John Hughlings Jackson married his first cousin, Elizabeth Dade Jackson, in July 1865. For eleven years they were very happily married, as is testified by his letters. In addition to her domestic duties, Elizabeth acted also as John's assistant, transcribing his writings for print. In 1876, after she had a short illness which included a probable septic thrombophlebitis, Elizabeth tragically died. During this illness she developed a succession of Jacksonian seizures, and it must have been a bitter irony for John to see his wife dying of the very type of fit which bore his name, and to the understanding of which he had devoted his life. Amongst her physicians were Sir William Jenner, Physician to the Queen and later President of the Royal College of Physicians, but his nuciform pustulations were to no avail. Elizabeth was buried in Highgate Cemetry, where are interred many of London's most distinguished inhabitants. Karl Marx is a famous spirit in the cemetery.

His political writings were a reaction against the contemporary fashion for hierarchical organisations, which was at the core of Hughlings Jackson's own neurological philosophy. Sparks probably fly on All-Souls night!



John Hughlings Jackson in later life

**Simon Shorvon**  
Co-editor, Epigraph

# Epilepsy in Chile

## The Gap between the Desirable and the Possible

Advances in the management of epilepsy in the developed world in recent years have created a perceptible 'gap' with less fortunate third-world countries, in regard to what is desirable and what can actually be achieved with limited and often scarce resources.

In promulgating the idea of this 'gap' it is clear that, in fact, there are a number of such gaps - historical, political, diagnostic/therapeutic and organizational, all of which profoundly affect the patients' prognosis, and operate in both 'international' and 'intranational' paradigms.

### International Gaps

What may be called the international historical gap relates specifically to the understanding of epilepsy as a health problem. For example, a gulf separates Chile, which has not a single epilepsy centre, from the European countries, where such centres began in the 19th century.

The international political gap refers to differences in planning and assignment of funds at the national level. In Chile there is no such planning for epilepsy, again contrasting with developed countries, where epilepsy health programmes have existed for several decades.



Children with epilepsy at the Hospital Calvo Mackenna

The amount of resources set aside for health in general, let alone for epilepsy, contrasts starkly in Chile with that in developed and even other Latin American countries. For example, in the US the figure is 14% of GDP, in Germany 10%, in Argentina 10%, in Costa Rica 8.5%, but in Chile 6.5%.

There is also an 'international gap in diagnosis' if we compare developed countries with Chile. The former enjoy a wide range of diagnostic techniques (including EEG, Magnetic Nuclear Resonance, the latest generation of computerized axial tomography (CAT), PET and SPECT scanning, biomolecular and molecular genetic studies and other developed medical equipment and methods), all of which are quickly accessible to patients in need. The latter has scant diagnostic resources and very long waiting periods for patients and researchers alike.

This stark gap between rich and poor countries was underlined at the International Morocco Conference of May 1999.

One of the chief differences between Chile and the developed countries concerns the

high cost of antiepileptic drugs (AEDs). Phenytoin and phenobarbitone are available to most patients and are subsidized by the State, but in Chile it is very difficult for most patients to obtain val-proate, carbamazepine and new AEDs, though these, too, are subsidized in the richer countries.

No less important is the 'surgical/therapeutic gap', though this was not mentioned in Morocco. This is no superficial matter, when we consider that 70% of people with epilepsy undergoing surgical treatment recover, thus diminishing the number of refractory patients and so lowering the long-term indirect costs to government. In Chile, however, although access to neurosurgery is relatively easy, this is not the case with regard to epilepsy surgery, since this requires prior specialized examinations which are unaffordable by most patients.

Lastly, there is an 'international organizational gap' with regard to patient care. As far as we know, there is no organized epileptic patient representative body in Chile apart from the Epileptic Children's Parents Association, which was acknowledged at the meeting of the National Association of Relatives and Friends of Mentally Handicapped People (ANAFADIS), on 25 and 26 November 1999 in Santiago.

### Intranational Gaps

Intranational gaps, too, are relevant. The percentage of GDP dedicated to health in Chile is 2.5% for public health and 4.0% for private health. This situation is reversed in developed countries. In health priorities epilepsy in Chile has no place, which leaves it, relative to the other 16 major classified diseases, at a serious disadvantage.

There is, moreover, a marked contrast in Chile between public and private access to diagnostic techniques. There was respectively a 13 and 9 year gap regarding access to CAT scanning, in comparison with developed countries (1969), with an average 4 year gap. In 1986 Chile was five years behind the developed countries in its use of MNR scanners in private health, while having no such devices in the public sector, producing an overall 18 year gap in public health in comparison with developed countries, and a 13 year gap in the private health sector. The use of these two vital diagnostic techniques is widening in Chile.

In the capital, Santiago, with a population of five million (a third of the whole population of Chile), there is one up-to-date CAT scanner in the private health sector and about seven in the public sector. The public health service does not have a single MRI scanner, although the private sector has at least four. Although the private health sector in Santiago has one laboratory capable of carrying out long-term studies of EEG, there is none in the public health sector.

In conclusion, the intranational diagnostic gap between public and private sectors is mirrored in the capital, which underlies how difficult it is for patients of limited resources to obtain

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## BRAZIL



The Brazilian League Against Epilepsy (BLE), the official Brazilian branch of the ILAE, was founded in 1949, celebrating its fiftieth anniversary in 1999. In honour of this anniversary, we have updated the BLE's history with a journal article and organized scientific meetings throughout the country. There were two special gatherings in Rio de Janeiro, where the BLE began. One of them was honoured with the presence of its founder, Dr Paulo Niemeyer.

Today the BLE is the strong voice of the epileptological community of Brazil. It holds an annual meeting and a biannual congress. The next event, 'Epilepsia 2000', will take place on 8-10 June at the Maksoud Hotel, Sao Paulo.

With the support of the pharmaceutical industry, the BLE has developed its own web site to improve communication amongst all professional members and patients alike. The address is: [www.epilepsia.org.br](http://www.epilepsia.org.br).

Together with the Brazilian Association Against Epilepsy (a branch of the IBE), the BLE is participating in the Global Campaign 'Epilepsy out of the Shadows', which aims to enhance recognition of epilepsy throughout the country, to disseminate information and encourage government to provide anti-epileptic drugs to epilepsy sufferers.

**Marilisa M. Guerreiro**

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## INDONESIA



In collaboration with the staff of the Department of Neurology within the Faculty of Medicine of the University of Indonesia, two prospective studies recently carried out were on the sonographic pattern of bone mineral density in women with epilepsy receiving long-term phenytoin at the Neurological Clinic of Dr. Cipto Mangunkusumo Central Hospital, Jakarta by Satya Hanura, and Aminotransaminase and Gamma glutamyl transferase in patients with epilepsy receiving phenobarbital, phenytoin and/or carbamazepine, also at the Neurological Clinic.

**Lily D. Sidiarto**

*e-mail: [sidiarto@indo.net.id](mailto:sidiarto@indo.net.id)*

### Have your say!

Contributions to the Bulletin Board are always welcome from any organisations or individuals with a 'story to tell'. Please e-mail the Epigraph Office: [j.solomon@ion.ucl.ac.uk](mailto:j.solomon@ion.ucl.ac.uk) or fax on +44 (0) 20 7833 2062 or write to Juliet Solomon at Institute of Neurology, 6th Floor, Queen Square, London WC1N 3BG, UK.

## SLOVAKIA



The Slovak League Against Epilepsy is continuing in its postgraduate activities. Our aim is to improve knowledge of epilepsy amongst neurologists.

We organized four weekend "School of epilepsy" courses in which epidemiology, patophysiology, diagnosis, differential diagnosis, social problems and therapy of epilepsy were presented. During the two days we presented more than 500 slides and video presentations of different seizure types.

We have just released our new book "Epilepsy - the guide book of diagnosis and therapy of epileptological seizures". The authors are: V. Donath, P. Sykora and M. Kuchar.

We are in the process of preparing the next Epilepsy Congress of the Slovak and Czech Leagues Against Epilepsy, which will be held in Presov (Slovakia) this year.

The main themes are (the main topics to be discussed are): 1: Rationale therapy in epilepsy, 2: EEG in epilepsy, 3: Controversies in epilepsy.

**Vladimir Donath**

*e-mail: [vdonath@isternet.sk](mailto:vdonath@isternet.sk)*

## SWITZERLAND



The Swiss League against Epilepsy (Schweizerische Liga gegen Epilepie or SLgE) is one of the very few chapters worldwide which is not only open to professionals but also to the lay public. Consequently, it is active in both scientific and social aspects of epilepsy. Currently the SLgE is working on an 'Epilepsy Report Switzerland 2000', which is sponsored by its research commission.

This report will summarize the current status of epilepsy care in Switzerland, define gaps, and contain proposals for overcoming identified weaknesses. As in preceding years, two journals were published - *Informationsschrift Epilepsie* is published twice yearly and is aimed at professional league members such as neurologists, neurosurgeons, paediatricians, psychologists, practitioners, teachers and nurses.

*Kontakte*, also published twice yearly, is for patients and their relatives, with topics related to everyday life and self-help. In addition, there is a variety of other informative material (for example, leaflets on various topics, a seizure diary for patients, and book lists) published in German, French and Italian.

In 1999 a first joint meeting of the Austrian, German and Swiss chapters of the ILAE was held in Vienna. It has been decided that in future this will be repeated every second year (the next meeting taking place in Zurich from 15-18 March, 2001). In addition, the annual meeting of the SLgE for

patients took place in Zurich in November. At the end of March 2000 epilepsy was included as a topic in the 'Brain Fair' as part of the 'International Week of the Brain'.

**Guenter Kraemer**

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## TURKEY



The Turkish National Epilepsy Congress is to be held in June 2000, during which a course on basic epilepsy etiology will be held, supported by EUREPA. Seminars on epilepsy and education have begun at primary and secondary schools under the auspices of the education committee of the Turkish Epilepsy Society. The first issue of Epibase, a bulletin on the Turkish epilepsy database, has been published, and contains results of an evaluation of the programme and information on epilepsy education.

**Candad Gurses**

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## Announcement

We would like to clarify a point which appeared in last issue's Bulletin Board. The National Epilepsy Law in Argentina was instigated by the Argentine Chapter of the ILAE and FUNDEPI.

## A New Benefit for ILAE Members!

*Epilepsia*, the official journal of the International League Against Epilepsy, is now available full-text, online at [www.epilepsia.com](http://www.epilepsia.com). Now, along with the advantage of subscribing to *Epilepsia* at reduced rates, ILAE members will receive the online edition FREE with a print subscription.

The site includes complete access to the full content of every issue; fast, easy search capabilities; all figures, legends, tables, and illustrations; and more rapid access to information for international subscribers.

For current subscribers, password access information is available on the website.

If you would like to subscribe to *Epilepsia*, which includes *Epilepsia Online*, please contact your Regional Chapter of ILAE.

## Epilepsy in Chile *continued*

high-quality epileptological diagnosis, which might offer some improvement in the prognosis, avoid premature deaths and enhance the quality of their lives. In greater Santiago all patients have access to phenobarbitone and phenytoin; some have access to valproate and carbamazepine, but none have access to AEDs of the third generation. Nor, as mentioned, is there anybody representing epileptics' interests, apart from the Parents' Association.

### Possible solutions

It is not the aim of this paper to propose theoretical solutions, but to emphasize those actions within Chilean epileptology that could help reduce the aforementioned gaps:

- 1) Support for the International League Against Epilepsy (ILEA) and the Chilean Society of Epilepsy, as its Chilean Chapter.
- 2) Support for the International Bureau for Epilepsy (IBE) and the National Association of Chilean Leagues Against Epilepsy, as its Chilean chapter.
- 3) Creation of a Commission (already in process), supported by the Ministry of Health, to formulate a Programme and Plan for Epilepsy in Chile.
- 4) To host in Chile a Latin American Congress on Epilepsy, at which Latin American 'Day of Epilepsy' will be declared on 9th September 2000 and a 'Declaration of Santiago for Epilepsy in Latin America' will be proclaimed.

## Conclusion

It is clear from the above not only that epileptology in Chile has a long way to go in reducing the gaps between it and the developed countries, in both public and private health, but that these gaps are rapidly widening, and not merely with regard to antiepileptic treatment. It is to be hoped that the measures already undertaken and others outlined for the future will help lead epileptology in Chile 'out from the shadows'.

**Dr Marcelo Devilat, President of the Chilean Epilepsy Society, Calvo Mackenna Hospital, Santiago, Chile**

**Email: [madevi@ctcreuna.cl](mailto:madevi@ctcreuna.cl)**

# 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).

## The Annual German Child Neurology Meeting, Kiel, Germany, 4-7 May 2000

There will be a full day session on the effectiveness of epilepsy surgery in treating childhood epilepsy as part of a general theme of evidence based medicine. The congress language will be in German, further information may be obtained from the organizer Prof. Stephani at:

e-mail: stephani@pedneuro.uni-kiel.de

## International Meeting on the Psychobiology of Epilepsy, Berlin, 6-7 May 2000

Information about registration (£100 sterling, or £50 for students) can be obtained from: Jackie Ashmenall, St Aiden, Ealing Green, Ealing, London W5 5EN, United Kingdom.

Tel: +44 020 7829 8743 / +44 020 7840 1287  
Fax: +44 0207 278 3053

e-mail: jashmenall@yahoo.com  
website: www.wai.co.uk/epilepsy

## Seventh European Conference - Epilepsy and Society 2000, Athens, Greece, 19-21 May 2000

Contact: Congress Secretariat, C&C International S.A., Conventions & Congress, 31 Arkadia Street, 115 26 Athens, Greece.

Tel: +301 74 83 401  
Fax: + 301 77 04 563

e-mail: candc@ath.forthnet.gr

## XVth Epilepsy Conference of the Polish League Against Epilepsy, Warsaw, Poland, 27-27 May 2000

Contact: The Congress Secretariat, Foundation for Epileptology, 122 Wiertnicza Str., 02-952 Warsaw, Poland.

Tel: + 4822 842 2492  
Fax: +4822 642 7434

e-mail: office@epilepsy.prg.pl  
website: http://www.epilepsy.org.pl

## The 4th Ethnean Epilepsy Workshop, St Thomas Convent, Linguagloss, Mt. Etna, near Toarmina, Italy, 9-11 June 2000

Contact: Dr Antonio Pavone, Neurology Department, Ospedale Garibaldi 95100, Catania, Italy

Tel/Fax: +39 095 31 21 52

e-mail: hespa@tin.it

## Kuopio Epilepsy Symposium 2000, Kuopio, Finland, 15-16 June, 2000

This will be the second in a series of epilepsy meetings that are organized jointly by the A. I. Virtanen Institute for Molecular Sciences and the Department of Neurosciences and Neurology, University of Kuopio. The objective of the meeting is to present the latest knowledge of selected topics related to epilepsy. Both experimental and clinical data will be presented. For further information please contact: Sari Koskelo, Secretary, A. I. Virtanen Institute, University of Kuopio, P.O. Box 1627, FIN-70211 Kuopio, Finland.

Tel: +358 17 162095  
Fax: +358 17 163030

e-mail: sari.koskelo@uku.fi

## The Annual Meeting of the German section of the ILAE (LIGA), in Heringsdorf on the Baltic Sea, 15-18 June 2000

It is the 40th annual meeting, the organizing president is Prof. U. Runge. The meeting consists of annual courses, plenary sessions and young researcher poster sessions. Topics include new aspects of seizure and epilepsy classification, developments in diagnosis, treatment and rehabilitation. Congress language is German. Further info may be obtained through the internet:

http://www.ctw-congress.de

## 11th International Cleveland Clinic - Bethel Epilepsy Symposium: Cortical Dysplasia and Epilepsy, Cleveland, Ohio, 27-30 June 2000

This meeting will be held at the Cleveland Clinic. The subject will be 'Cortical Dysplasia and Epilepsy: Pathophysiology, Diagnosis and Management'. The International Symposium will be preceded by two related meetings: The Comprehensive Course (22-25 June 2000) and Neuroimaging and Epilepsy (26 June 2000). For further information call:

Tel: +216 444 5178  
Fax: +216 444 0230.

## Nature and Nurture in Epilepsy and Psychiatry - Implications for New Treatment Strategies, Oslo, Norway, 30 June-2 July 2000

Contact: Ms Kirsten Haga, Department of Anatomy, University of Oslo

Fax: +47 22 85 12 78

e-mail: k.s.haga@basalmed.uio.no

## 2nd Asean Neurological Association (ASNA) Epilepsy Conference 2000 and 4th Indonesian Neurological Association Congress, Surabaya, 1-4 July, 2000

In collaboration with staff of the Department of Neurology of the University of Indonesia's Faculty of Medicine, results of several studies relating to epilepsy are to be presented at the joint congresses of the 2nd Asean Neurological Association Epilepsy Conference 2000 and the 4th Indonesian Neurological Association Congress in Surabaya in July. On 3rd July PERPEI's Biannual Meeting will be held.

e-mail: sidiarto@indo.net.id

## The First International Symposium on Epilepsy, Infantile Spasms, and Developmental Epileptic Encephalopathy, Seattle, Washington, USA, 21-23 September 2000

The meeting will provide a critical analysis of the basic mechanisms underlying infantile spasms and related epileptic encephalopathies of childhood. For further information, contact the PERC, University of Washington, Box 356470, Seattle, WA 98195-6470, USA.

Tel: +206 221 5364  
Fax: +206 221 5721

e-mail: perc@u.washington.edu

## Third Etnean Epilepsy Symposium Linguaglossa, Italy, 24-25 September 2000

Contact: Dr Pavone Antonio or Dr Sicurella Luigi, Neurology Department, Ops. Garibaldi, 95100 Catania, Italy.

Tel/Fax: +39 095 31 21 52

e-mail: hespa@tin.it

## Fourth ILAE European Congress on Epileptology Florence, Italy, 7-12 October 2000

Contact: Secretariat, PTS Congress, Via Tever 20, 00198, Rome, Italy

Tel: +39 6 8535 5590  
Fax: +39 6 8535 6060

e-mail: ptscongr@tin.it

## 54th Annual Meeting of the American Epilepsy Society, Los Angeles, California, U.S.A., 1-6 December 2000

website: http://www.aesnet.org/conference/index.htm.

**President:** Jerome Engel, Jr, MD, PhD, Reed Neurological Center, UCLA School of Medicine, 710 Westwood Plaza, Los Angeles, CA 90095-1769.

Tel: +1 310 206 5871. Fax: +1 310 206 8461. e-mail: engel@edu.ucla

**Secretary-General:** Peter Wolf, MD, Epilepsie-Zentrum Bethel, Maraweg 21, D-33617, Bielefeld, Germany.

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