

Epigraph

THE NEWSLETTER OF THE INTERNATIONAL LEAGUE AGAINST EPILEPSY

ISSUE 1 2001

Editorial

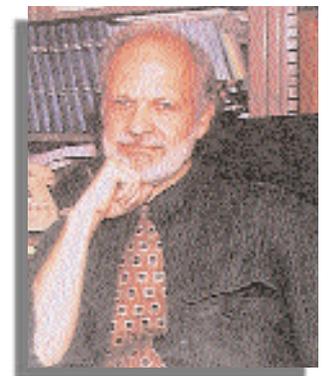
This is the last issue of *Epigraph* of the term of the current Executive Committee, and in May, the new Executive Committee will start its work. Dr Pete Engel, the outgoing ILAE president, gives a good summary of the work of the last four-year term in his last presidential message. A great deal has been achieved, and we owe a great debt of thanks to Dr Engel, and to Dr Peter Wolf and Dr Giuliano Avanzini, the outgoing secretary general and treasurer, for their tremendous energy and work on the management team of the ILAE, during the past 4 years. They leave the ILAE a bigger and better organisation, stronger financially and stronger numerically, broader in range and greater in depth. All members should have benefited by better services and greater involvement; this has indeed been an active period of growth for the ILAE. The president-elect Giuliano Avanzini also contributes an article in this edition, laying out some plans for the future and some of the principles which will underpin his term over the next four years. We wish him well in this endeavour - and it is noteworthy too that the election of a distinguished scientist to our top position is a powerful signal of the importance which is now placed on academic issues in our organisation. The publication of this edition is co-incident with the 24th International Epilepsy Congress, in Buenos Aires; the epilepsy congresses have grown in size and stature in recent years, and the 24th congress promises to continue the trend. Dr Fejerman writes about the conference on page 6, and emphasises the Tango-oriented fun as well as the science. The Global Campaign, designed to raise awareness of epilepsy worldwide, has been another tremendously successful initiative, driven on the ILAE side by Dr Ted Reynolds, a report on progress is given on page 4. Dr Reynolds and his team have achieved remarkable success by establishing the Global Campaign as a cornerstone of WHO policy and by gaining cabinet-level status in the WHO. *Epigraph* also contains its regular features - the diary dates and bulletin board and its historical snippets (this time an excellent piece on St Birgitta). All members are invited to contribute to these items, to make the newsletter two-way and interactive, which is its purpose and intent.

Simon Shorvon, Co-Editor

President's Message

A Time of Growth

The past four years have gone quickly, and the time has come for my last message in *Epigraph* as President of the League. I have had the honour of serving this organization as Treasurer from 1993 to 1997, and then as President until the General Assembly next meets during the International Epilepsy Congress in Buenos Aires in May. This has been a time of transition, of which I am proud to have been a part. As this four-year executive term comes to an end, it is appropriate to reflect on how the ILAE has changed in recent years.



The past two Executive Terms have seen tremendous growth in League affairs (2,000 delegates attended the Oslo congress in 1993 and 4,500 attended the Prague congress in 1999; there were 40 national chapters of ILAE in 1993 and there are 77 at present; the League's assets in 1993 were approximately \$600,000, with an annual budget of approximately \$100,000, while this year we have nearly \$3,000,000, with an annual budget approaching \$1,000,000). This growth, however, is merely the reflection of a gradual conceptual transition of the League from an organization that existed predominantly as a central umbrella office for its many national chapters, to a much more proactive organization committed to improving research on, and clinical care for, epilepsy worldwide. Our mission is now being realized not only through our national chapters, but also in association with the International Bureau for Epilepsy (IBE), the World Health Organization (WHO), and on our own. The current status of our metamorphosis has been officially recognized, and publicized, in the form of the first-ever ILAE Vision Statement and Strategic Plan (see *Epigraph*, 2000, Issue No. 2). These documents represent the legacy of the last two Executive Terms, to be translated into even more definitive action by President-elect Giuliano Avanzini and the members of the next ILAE Executive Committee.

Increased financial responsibilities

Perhaps the most important aspect of the League's deliberate decision to reformat itself and more actively pursue its global mission has been its progressive professionalization. A significant increase in annual income for the League initially occurred during my tenure as Treasurer, due to the enhanced prestige of *Epilepsia*, under the effective editorship of Tim Pedley, which grew from six to twelve issues a year with many supplements, and to the great success of the International Epilepsy Congresses. Surpluses in the ILAE accounts resulting from both of these efforts derive indirectly from our improving relationship with the pharmaceutical industry, which advertises and publishes supplements in *Epilepsia*, participates in our international congress with satellites and exhibits, and sponsors many delegates to these meetings. Two facts became evident toward the end of the last Executive Term, which greatly influenced major changes enacted by the present Executive Committee. First, we realized that our increasingly solid financial situation depended almost entirely on the pharmaceutical industry, and that it was unwise to expect that their interest in epilepsy, and sympathy with the global efforts of the ILAE, would necessarily last indefinitely.

Continued on page 2

IN THIS ISSUE



Education of Young People with Epilepsy - Chile p5



Buenos Aires Conference p6



Was St. Birgitta suffering from epilepsy? p7

ALSO

Diary Dates p8

Bulletin Board p7 & 8

President's Message *continued*

Second, it was painfully obvious that I, as a neuroscientist and physician, was no longer competent to deal with the complex nature of the League's finances, and that professional financial management was necessary.

Professional financial management

As a result of these realizations, one of the first actions of the present Executive Committee was to hire a professional organization, led by Peter Berry, to manage our financial affairs. With the new Treasurer, Giuliano Avanzini, they established a central accounting system and an investment policy that would ensure the League's financial security into the foreseeable future. Consequently, during this Executive Term we were able to carry out the first formal annual audits, required by our constitution, and to defend ourselves against a recent challenge by the United States Internal Revenue Service. If we had not had our accounts in order, and effective knowledgeable representation, this challenge would have caused us to partially lose our non-profit status and required us to pay hundreds of thousands of dollars a year to the United States government. Our increased annual surplus is now being used to support the many new activities of the League.

Professional congress organization

With the tremendous growth of the International Epilepsy Congresses, involving multimillion dollar budgets, as well as the initiation of regional congresses on alternate years in Europe, Asia and Oceania, and most recently Latin America, the present Executive Committee also realized the need to professionalize this important aspect of our activities. Consequently, in association with the IBE, we hired Richard Holmes as our International Director of Meetings, to maximize not only the financial, but also the scientific and political, benefits of these events. By having our own congress organizer, and bringing these meetings under more direct control of the ILAE and IBE Executive Committees, we have also ensured a greater degree of consistency from one meeting to another, and provided opportunities for some of these congresses to be held in developing countries that do not have the resources to manage such a major undertaking on their own.

New Epilepsia contract

Our new contract with Blackwell to edit *Epilepsia* has guaranteed that our journal will continue to be a reliable source of income for the League over the next five years. Its continued success as a scientific journal, of course, will depend on the next Editor, who will be appointed by Prof. Avanzini and his Executive Committee, and who will take office in January 2002. The nature of this contract not only preserves *Epilepsia's* role as a generator

of the League's financial surplus, but also guarantees that some of this surplus will be used to improve dissemination of the information contained in the journal, through even greater discount subscription rates to members of our chapters, and inexpensive or free distribution of relevant papers to developing countries through *Epilepsia* Digest and the Internet.

Chapter development and regional organization

The extraordinary growth over the past eight years in the number of our national chapters can be attributed largely to the dedication and hard work of Peter Wolf, Secretary-General for the past two terms. Prof. Wolf was particularly responsible for chapter development in Europe, and for setting the stage that has led to the extremely successful regional organization of our European chapters. Chapter development and regional organization have also been aided by the regional commissions under Martin Brodie for Europe, Masakazu Seino for Asia and Oceania, André Palmi for Latin America, and William Theodore for North America. Plans for a Commission on African Affairs are underway, as well as official recognition of inter-regional organizations, including the Mediterranean League, the Pacific Rim region, and the Pan Arab League. Developing these localized, but still inter-national activities represents an important new role for the League. Whereas League efforts in the past had been purely global, it is clear that facilitation of interactions among national chapters at a more local level are at least equally important in achieving ILAE goals and objectives.

The Global Campaign

The Global Campaign, initiated by Edward Reynolds while President during the past Executive Term, in collaboration with IBE and WHO, has become the flagship for almost all League efforts to improve the acceptability, diagnosis, treatment, and prevention of epilepsy worldwide. The Global Campaign now has maximum visibility among government health agencies by virtue of its promotion to the highest priority cabinet level by the WHO, with re-launch at a ceremony in Geneva on February 12, 2001, during which the Director-General, Dr. Gro Harlem Brundtland spoke in support of the epilepsy movement. Although the Global Campaign is focused primarily on improving the social and medical status of people with epilepsy in the developing world, it is also concerned with increasing the epilepsy budget, not only for health care but also for basic research, in industrialized countries. Our resource commissions, Neurobiology, under Phil Schwartzkroin, Neurosurgery, under Heinz-Gregor Wieser, Psychobiology, under Michael Trimble, and Pediatrics, now under Renzo Guerrini, as well as our problem-oriented commissions, on the Burden of Epilepsy, under Torbjörn Tomson, Developing

Countries, now under Ley Sander, Search for Epilepsy Genes, under Elving Anderson, Diagnostic Strategies, under Martha Morrell, and Therapeutic Strategies, under Richard Mattson, and their many subcommissions, have achieved much during this Executive Term, for the most part relevant to the goals and objectives of the Global Campaign. These accomplishments of our commissions are too numerous to mention here, but they should be documented in a later issue of *Epigraph*.

Dissemination of information

The International League against Epilepsy should be the primary authoritative source of information on epilepsy, not only for its chapter members, but for all individuals worldwide interested in epilepsy. During this administration the ILAE has addressed this responsibility through *Epilepsia* and *Epilepsia Digest*, as noted previously, and *Epigraph*, co-edited by Simon Shorvon and Ley Sander, which is now mailed twice a year to all members of every national chapter. The Executive Committee has also recognized the need for a portal website on epilepsy, which has been envisioned as a one-stop shopping center for epilepsy. Although progress continues in this direction, for a number of reasons this project has not been completed, and its ultimate realization will now be left to the next Executive Committee. In the meantime, however, no other website has assumed this role, and the need for such a central information source, which will also link to the many excellent, but non-comprehensive, epilepsy sites that currently exist, remains. The revision and update of the international classifications for seizures and epilepsies have also been important informational objectives for this Executive Term. A dynamic flexible system has almost been completed, which will provide opportunities for continuous revisions as our knowledge base grows. Rather than ask the General Assembly, in Buenos Aires, to approve another static classification system, we will more likely be asking them to approve a concept, which will continue to be a work-in-progress during the next Executive Term. It has not been easy to reach agreements on terminology and classification among the professional leaders in the field of epileptology. An accepted terminology and classification system is essential for effective communication, but it also shapes our thinking about epilepsy itself. Consequently, achieving a mechanism whereby discussions about terminology and classification can be a continuing process should be a high priority for the next Executive.

Administrative considerations for the future

Finally, just as my incompetence as Treasurer during the last Executive Term resulted in the League seeking professional financial

management, I have found that the growing administrative responsibilities assumed by the President during this Executive Term have now outstripped my competence. Consequently, I hope that the next Executive Committee will agree to establish a permanent Executive Office with a professional Executive Director for the League. It is clear that the many important ILAE activities currently underway, and planned for the future, have become much too diverse and complex to be adequately administered by inexperienced volunteers like myself. The next step in the maturing of organizations such as ours is the establishment of a proper permanent Executive Office with professional staff, which is not linked to, or dependent upon, any one of its transient volunteer officers. Such an office would not only be maximally responsive to chapter needs and provide optimum administrative support for all officers and commissions, but also ensure important continuity from one Executive Term to the next. With modern advances in electronic communication, a central Executive Office could be located literally anywhere in the world; however, international organizations such as ours still need to take into account logistical and political concerns in deciding how to choose an Executive Director, and what the official address of the Executive Office ought to be. These are knotty issues which Prof. Avanzini and his Executive Committee will need to face early during the next executive term.

Jerome Engel, Jr
President

International Epilepsy Resource Centre

As featured in previous editions of *Epigraph*, the joint IBE/ILAE International Resource Centre is now fully operational, based at the Swiss Epilepsy Centre in Zurich. The function of the centre is to collect, evaluate and archive all ILAE and other resource material on epilepsy from around the world. The collection includes a range of materials including: fact sheets, pamphlets, booklets, books, guidelines, posters, material relating to audit or standards of practice, details of regular courses, videos. A computerised database is now on-line with over 800 items, and the index is available to all ILAE members. With time, this will become a valuable collection and should be a stimulus towards the world-wide integration of ILAE knowledge and information. We urge all members to submit material to, what will become, a comprehensive and complete collection. Please send material to:

Dr Ian Mothersill. ILAE/IBE Resource Centre.
Swiss Epilepsy Centre. Bleulerstrasse 60. CH-8008.
Zurich. Switzerland. Tel: +41 1 387 6202;
Fax +41 1 387 6249; e-mail ierc@swissep.ch.

The ILAE of the next millennium: where do we go from here?

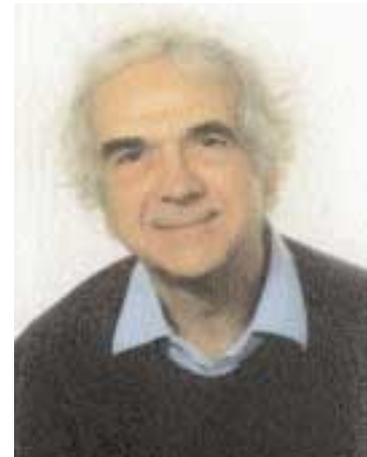
I feel greatly honoured by the fact that I have been elected to serve as the President of the ILAE for the next term, and willingly accept the challenging task of promoting the further development of our already extremely active association.

Over the last ten years, the ILAE has greatly expanded its scope worldwide, as the almost double number of Chapters testifies. Not only clinicians, but also basic scientists have found our joint ILAE/IBE International Congresses increasingly attractive. Furthermore, we have been able to hold an ever growing number of educational and training courses in many parts of the world. Our journal *Epilepsia* has become increasingly successful both in quantitative and qualitative terms, and our *Epigraph* newsletter has greatly improved our communications with our 16,500 Chapter members. ILAE Commissions have produced guidelines, position papers and educational material concerning the most important aspects of our discipline, and our synergistic work with the IBE has led to the creation of two major joint initiatives: the ILAE-IBE International Resource Center and the ILAE-IBE-WHO Global Campaign against Epilepsy.

Our structural organisation clearly needs to be further developed in order to meet the requirements of such multifaceted activities but we must preserve the flexibility necessary to avoid the danger of bureaucracy. We can take heart from the success of the decisions of the current Executive Committee of creating ad-hoc professional offices to proceed along this way, in line with the Strategic Plan (*Epigraph 2000*, Issue no. 2).

Particular care needs to be given to improving interactions with national Chapters. A first step in this direction will be made with the completion of the ILAE website, which will make ILAE activity documents readily available to Chapters and thus create a permanent discussion forum. However, further efforts should be made in order to ensure that Chapter members feel actively involved in the life of the ILAE, without losing anything of their specificity as members of their national Chapters, which should continue to play a central role in mediating communications with the ILAE.

Although much has been done to fulfil the ILAE's mission of spreading the benefits of its actions to everybody suffering from epilepsy the results are still unsatisfactory:



Giuliano Avanzini

in particular, some developing regions are still insufficiently covered by the ILAE Chapter system, and there are still too few Congress delegates from the Chapters established in developing countries. There is no doubt that one of our strategic priorities must be that of bridging the gap between the "developed" and "developing" world by allowing developing countries to have more say as to what is "good for themselves" rather than accepting what others think is "good for them". Our main challenge is that of ensuring that our aim of establishing the highest scientific profile of ILAE activities matches the objective of promoting the active involvement of qualified people from less technologically advanced areas. In order to do this successfully, we need to concentrate on making the most of the resources generated by our partnership with industry: our friends in the pharmaceutical industry have to understand that, although their final objective of profit is different from ours, we have the shared interest of improving epilepsy care throughout the world.

As you can see, there is enough to keep the next ILAE Executive Committee busy with demanding, but also exciting activities, the results of which I look forward to seeing in the near future.

Giuliano Avanzini, President-elect

Coming 'Out of the Shadows' in Geneva

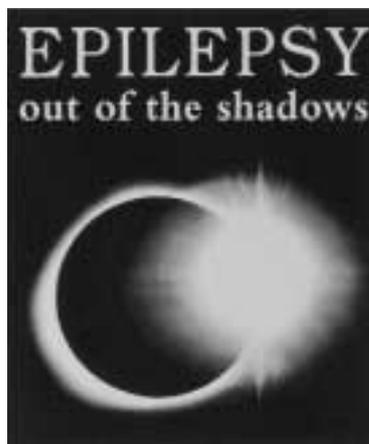
Since the summer of 1997 the Global Campaign Against Epilepsy has been gradually gathering momentum. This collaborative programme of the ILAE, IBE and WHO has led to Regional Conferences and Declarations around the world which have endeavoured to encourage greater prioritisation of epilepsy services. It has also led to WHO accordng the Global Campaign Cabinet-level status within its own organisation.

Now, after the 3-4 years of such awareness-raising, the Global Campaign is beginning to enter its second phase of practically assisting Ministries of Health to reduce both the epilepsy treatment gap and the burden of epilepsy. (Such assistance is initially being provided through various Demonstration Projects in developing countries). It was this second phase which formed the basis for a two-day meeting at WHO HQ in Geneva on 12-13th February.

The Launch of the 2nd Phase was attended by over 100 people, consisting of representatives from ILAE and IBE Chapters, other NGOs and representatives from pharmaceutical companies. More importantly, representatives from each of the WHO Regions (Africa, the Americas, Eastern Mediterranean, Europe, South-East Asia and Western Pacific) were present. Their participation augurs well for the Campaign's future, as does all the hard work behind the scenes of the Noncommunicable Diseases and Mental Health Cluster in WHO HQ and their continued efforts on behalf of the Global Campaign. Mr John Bowis, a Member of the European Parliament, provided further encouragement through his attendance and public desire to move epilepsy higher up the European health agenda.

Most importantly, the Director General of the WHO, Dr Gro Harlem Brundtland, was present at the Launch. Her opening speech

declared both her and WHO's commitment to the Global Campaign and to "bringing epilepsy out of the shadows". She acknowledged the huge burden of epilepsy on the 50 million people with the condition across the world, and desired to see treatment provided for the many millions who do not yet receive it. Her presence provided a welcome and high-profile boost to the Campaign's efforts. Indeed, she even found time amidst her busy schedule to attend the evening reception to receive a rather large candle (symbolising light casting out the shadows of epilepsy) and be party to numerous photocalls.



As well as Dr Brundtland's speech, the morning session included a review of the Global Campaign (by Ms Hanneke de Boer, chair of the Campaign's Secretariat and representing the IBE), its history (by Dr Ted Reynolds, also of the Campaign's Secretariat and representing the ILAE), and an outline of epilepsy in the world today from both a medical (by Dr Pete Engel, President of the ILAE) and a social point of view (by Mr Phil Lee, President of the IBE). Mrs Carol D'Souza from India provided a moving description of her own

experience of epilepsy and of the stigma which still surrounds the condition. A press conference followed and it provided the Global Campaign with time on radio and TV across the world, as well as space in print media.

The afternoon and following day saw more practical details being discussed, namely how to go about implementing the Demonstration Projects across the world. Dr Ley Sander introduced the concept of the Projects - that they are attempts at devising sustainable approaches to providing epilepsy care in contexts of minimum resources. Discussions followed concerning the content of the Projects, particularly regarding the anti-epileptic drug treatment on offer.

Over the two days the WHO Regions also developed action plans and it is hoped that soon 1-2 projects will exist in each of the six Regions. The Projects currently being designed for Argentina, Senegal and Zimbabwe were discussed and these should begin later in 2001. The Project in China, however, began late last year and is already able to report new findings. For example, the prevalence of epilepsy appears to be 50% higher than first thought and the treatment gap seems to be more than 60%, rather than approximately 50%.

The two days ended with a feeling that the Global Campaign may now be gaining enough participation and commitment for it to truly be an effective vehicle for improving the situation of people with epilepsy. Let us hope that such feelings lead to concerted action from all those involved and that the shadows of epilepsy dispelled in Geneva recede across the rest of the world also.

For further information about the Global Campaign please visit www.who.int/mental_health/Topic_Epilepsy/Epilepsy1.htm or email Hanneke de Boer at hdboyer@xs4all.nl and for information about the Demonstration Projects in particular please contact Professor Ley Sander at l.sander@ion.ucl.ac.uk.



The picture shows some of the people who attended the launch of the 2nd phase of the Global Campaign against Epilepsy in February. In the front row (from left to right) are: Prof Jerome P. Engel, *President ILAE*; Mrs Hanneke M de Boer, *Chair of the Executive Board of the ILAE/IBE/WHO/Global Campaign against Epilepsy*; Dr Derek Yach, *Executive Director, Non-Communicable Diseases and Mental Health Cluster, World Health Organisation*; Mrs Gro Harlem Brundtland, *Director-General, World Health Organisation*; Dr Benedetto Saraceno, *Director, Department of Mental Health and Substance Dependence, World Health Organisation*; Dr Leonid L Prilipko, *Programme Leader, Neuroscience and Neurological Disorders, Department of Mental Health and Substance Dependence, World Health Organisation*; Dr Edward H Reynolds, *member of the Secretariat of the Global Campaign*; Mr Philip Lee, *President IBE*.

The Education of Young People with Epilepsy – A positive example from Chile



When it comes to education, the reality for people with epilepsy is often one of missed opportunities, lack of access and poor performance. Studies of children with epilepsy have shown that epilepsy has a negative impact on academic performance, may lead to cognitive difficulties (such as, memory and concentration problems), leads to a lower probability of reaching higher education or finishing school education, increases the likelihood of needing to repeat school and may cause higher rates of absence / truancy. This impact can be attributed to several factors including epileptic crises themselves, secondary effects of antiepileptic drugs or the burden which stigma and fears related to epilepsy have on a person.

A Chilean Response

The Liga Chilena Contra la Epilepsia (LICHE) - the Chilean League Against Epilepsy - has developed programmes designed to address these educational difficulties. One of these programmes is the Pre-University Course which aims to reverse the low probability of people with epilepsy reaching university.

Pre-University Course

The Pre-University Course was developed in 1999 for training young people with epilepsy who are undertaking their final or penultimate school year. It is also designed for young people who finished their secondary schooling 2 or 3 years previously but need preparation for the National Examination "Prueba de Aptitud Académica". The idea for this Course arose from LICHE's work with university students with epilepsy and it is open to any such students regardless of their grades. The total cost of the programme in 1999 was around US\$3,500. (This is almost the same as the cost of one year of private pre-university tutoring for one only student).



LICHE classes.

A central part of the Course is that those students who were helped by LICHE to fund their treatment or to gain university entrance then help others to gain their entrance to university. In 1999 the programme worked with 13 students (3 women and 10 men) and in 2000 this increased to 18 young people (10 women and 8 men). Most of the students come from the public schools system and their educational achievement is low. However, every student on the Course is characterised by motivation and enthusiasm to learn.

The Course's objectives consist of:

- Helping young people with epilepsy to gain access to higher education.
- Motivating students to participate in classes and to complete the whole course.
- Creating an atmosphere of companionship and solidarity in the group.
- Providing vocational help.
- Improving the possibility of access to employment requiring higher qualifications.
- Improving their quality of life.

The classes are carried out in an educational centre belonging to LICHE in Santiago and they are given by university students and lecturers with epilepsy or are associated in some way with the condition. Every month the Course's Coordinator evaluates the students' performance in a variety of subjects, such as Mathematics, Language, History and Geography, according to the Ministry of Education's curriculum. From this, each tutor designs an individual work plan for each student. The teaching materials themselves were given as donations.



LICHE HQ in Santiago.

An evaluation of the project has shown it to be of benefit both educationally and socially. The students found it important that the courses were given by young people with epilepsy because this heightened their own motivation to study. Whilst a small number of students did leave the Course, they did so because their families needed their help and not because of the Course's failings. In the 1999 group, three students entered university to study Agronomy, Teaching English and Human Resources Administration. This compares favourably with the national average of around 30% of people who apply for university gaining entry. As well as these educational achievements, the parents of the students also noticed an improvement in their children's quality of life.

This Course is one practical way of reducing epilepsy's burden on people. It has positively impacted on people's education and hence their employment prospects, hopes and aspirations. It is hoped that it can continue to successfully improve young people's quality of life.

Dr Carlos Acevado Sch MD



Welcome to the 24th International Epilepsy Congress in Buenos Aires

We are really glad to welcome you to Buenos Aires and I hope you will enjoy the meeting.

During international events, one cannot separate science from the place where it takes place. Our Congress has to be good on scientific grounds and this aspect seems to be well covered, considering the faculty members involved in the main, post main, parallel and simultaneous sessions, and the quality of the abstracts.

It is also important for people coming from abroad to feel happy not only in the city but also when visiting the country. Starting with the Opening Ceremony on Sunday and the Colon Theatre music performance on Monday up to the 'tango-oriented' Closing Banquet on Thursday, you will need to be prepared for an intense week; mixing knowledge on epilepsy, knowledge about people with epilepsy, friendship among colleagues plus the pleasure of enjoying art, culture and the city itself. What is more,

I recommend that you not only try to visit the city of Buenos Aires but also some of the beautiful places Argentina has to offer.

Your satisfaction is our responsibility and I am sure you will not be disappointed.

Buenos Aires

The city offers its visitors an ample choice of entertainment, ranging from its renowned good food (its famous steaks) to sight-seeing and the chance to enjoy an exciting night-life.



Natalio Fejerman, MD
Chairman International
Organising Committee
& Scientific Advisory Committee



Learn how to dance Tango

The Congress will offer all registered participants a free opportunity to learn how to dance Tango!



INTERNATIONAL TRAVEL GRANTS

The Epilepsy Foundation invites applications for its Fritz E. Dreifuss International Travel Program.

The program is intended to promote the exchange of information and expertise on epilepsy between health care professionals of the United States and foreign countries. Inquiries are invited from any health care professional dealing with patients with epilepsy, and are not limited to any specific degree category or level. At least one party in the exchange must be from the United States.

Successful applicants will receive funds for travel expenses. Funds for housing, meals, or local transportation are not provided through this program.

Applications are accepted throughout the year.

For further information, including applications, visit our website:

<http://www.epilepsyfoundation.org>

Or contact:

Epilepsy Foundation
Dreifuss International Travel Program
4351 Garden City Drive
Landover, MD 20785-2267
USA



phone: (301) 459-3700
fax: (301) 577-2684
e-mail: grants@efa.org

Famous People with Epilepsy

Was St. Birgitta suffering from epilepsy?

St. Birgitta (1303-1373) was canonized in 1391. She was born of noble lineage as the daughter of a president of court, married to a knight and later became a lady in waiting to Queen Blanca. Birgitta gave birth to eight children from her marriage with Ulf Gudmarsson. She belonged to powerful circles in medieval Sweden. She had frequent communications with priests, especially the great theologian Master Mattias of Skänninge, who was her confessor and who later interpreted her visions.

The late Professor of anatomy Carl Herman Hjortsjö, Lund, Sweden, took great interest in St. Birgitta, mainly because of his interest in medical archeology and osteology, which resulted in the formation of "The Swedish Expedition of Archeology and Anthropology" in the fifties, and later his eagerness to examine the bones in the shrine of St. Birgitta. He and his partners Bygdén and Bergvall scrutinized the two skulls of the shrine and determined which of them was most likely to have belonged to St. Birgitta. The cranium displayed some pathological features, such as hyperostosis frontalis interna and, especially, an excavation in the calvarium which corresponds to a similar elevation on the exterior. In his anatomy lectures, Professor Hjortsjö suggested to his students that a meningioma may have caused these osteological abnormalities and as a clinical result, a possible epilepsy.

When studying the photographs taken by Hjortsjö and published in the book "Heliga Birgittas relik" it is obvious that if one considers a meningioma it should be a meningioma of the convexity. The temporal regions, more interesting considering a



St. Birgitta of Vadstena in Sweden was recently nominated as a Patron Saint of Europe by the Pope. Did she have epilepsy? The picture shows a sculpture of St. Birgitta in Visingsö, Sweden, late 16th century.

history of hallucinations and religious experiences, are not visualized. On the other hand, meningiomas can of course be multiple.

Are there any other features in the history of St. Birgitta which would support epilepsy?

Yes and no. Her childhood development was not strictly normal. Her mother was subject to a drowning accident when she was pregnant with Birgitta. The child was mute until the age of more than three years; then she could speak fluently over the period of one night. St. Birgitta was around seven years old when she experienced her first revelation; in the night she could see a woman in shining clothes who gave her a precious crown. Some years later she experienced a

terrifying revelation which was interpreted as being caused by the devil. The latency period described as until around 1344 (when the revelations as a grown up appeared) may fit with temporal lobe epilepsy. Interestingly, Birgitta herself did often not know how to interpret her visions - the religious content was sometimes elaborated by her confessor.

The revelations are characterized by a lively metaphorical language, long descriptions with many detailed attributes, which stand in contrast to the most common hallucinations in epilepsy, which often are stereotyped and difficult to describe. The fact that St. Birgitta took great interest in the political life in Europe and used her powers to support or counteract popes as well as kings, has been used as an argument against true religious experiences.² In the discussion of a potential epileptic disease, this leads us to the possibility of functional (psychogenic) seizures or a combination of genuine and functional epilepsy.

Anyway, I presume that the *Epigraph* reader has a great enough faith not to be misled by a little tuberculum in an ancient cranium - it is only the deed of the tempter to seduce a contemporary seeker...

**Anne-Marie Landtblom MD PhD
Sweden**

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1. Bygdén A, Gejvall NA, Hjortsjö CH. Heliga Birgittas relik. Gleerups förlag, Lund, Sweden, 1954.
2. Furuhausen H. Furstinnan av Närke som blev Heliga Birgitta. Norstedts förlag, Stockholm, Sweden, 1990.

Bulletin Board

News from correspondents...

ITALY



FIRST EPILEPSY AMBASSADORS DINNER

On the occasion of the European meeting in Florence, Dr Canger organised the First Awards Dinner. This award is given by the ILAE in conjunction with the IBE. It is hoped that the award's dinner will become a regular feature of future epilepsy meetings.

PORTUGAL



The address of the Portuguese League has changed, please note our new contact details:

**Avenida da Boavista, 1015 - 6º, Sala 601
4100-128 Oporto, Portugal**

Tel/fax: +351 22 605 549 59

e-mail: mailto:epicentro.porto@oninet.pt

We also now have an office in Coimbra:

**Avenida Bissau Barreto, 268-1ª
3000 Coimbra, Portugal**

TURKEY



The use of a Turkish Epilepsy database programme that was initiated by Dr. Mustafa Ertas in 1998 in ten centres has spread widely since then. An Epibase sub-commission was founded within the Turkish Epilepsy Society in 2000, after which the number of centres who use the programme increased to 19. The data of 3,692 patients, 1,872 of whom were females and 1,820 of whom were males, was recorded. An Epibase bulletin was prepared to inform everybody concerned with epilepsy about the programme and its results. The fourth issue of this is about to be published. The 4th National Epilepsy Congress will take place in the second week of June 2001 and Epilepsy days will be held simultaneously.

Dr. Candan Gurses



Continued on page 8

TURKEY



Epilepsy surgery is improving rapidly in Turkey, as it is world-wide. In our country there is a growing interest in this subject and the number of specialists is increasing accordingly. There are approximately 600,000 patients with epilepsy, 60,000 of who have medically intractable epilepsy in Turkey, 15,000-25,000 of these are surgical candidates. To meet this demand, multi-disciplinary teams are required. There is a need for expertise in epileptology, neurophysiology, neurosurgery, neuroimaging, neuropsychology and neuropsychiatry for preoperative assessment. This multi-disciplinary team must be complete for an efficient presurgical assessment. Nine centres which have multi-disciplinary teams perform epilepsy surgery. The other centres which do not have multi-disciplinary teams refer their patients to these centres. It is hoped that there will be more centres equipped to perform epilepsy surgery in the not too distant future. There is a single article entitled 'Surgical outcome of epilepsy patients evaluated with a non-invasive protocol' in *Epilepsia* 41 (suppl 4) S41-S44 2000 that provides data from one of the centers in Turkey. When long term monitoring for ictal recording, high resolution MRI protocol and neuropsychology assessment with WADA (when required) are concordant with each other, the patient is considered to be an appropriate candidate for epilepsy surgery. Although the number

of patients who have undergone epilepsy surgery are still few, the outcome of the surgery is satisfactory and complies with the literature. In the near future with the use of invasive neurophysiology and structural neuroimaging supported by PET, the cases with discordant results will be examined and hopefully enough evidence to determine the right side for surgery will be provided.

Turkey as a developing country has a bright prospect in the field of epilepsy surgery.

Dr. Candan Gurses

URUGUAY



An Epilepsy Surgery Group is being developed in Uruguay, providing an important tool in the management of epilepsy. Presurgical assessment of patients with epilepsy and a selection of candidates for surgery is presently taking place.

In the past year our chapter has written and produced a video aimed at the general public, which has focused on general and clinical aspects of the disease. It answers the questions most frequently posed by patients and their families, and it will be of great help during the seminars that our chapter often organise as part of our educational programme.

Dr. Diana Yorio

USA



(Abridged-taken from American Epilepsy Press Release). In December 2000, Solomon (Nico) L. Moshe, M.D. was elected President of the American Epilepsy Society (AES) at the Organisation's 54th Annual Scientific Meeting. Moshe whose new office is effective immediately said his goal is to enhance communication and the transmission of information, building on the momentum achieved by his predecessors in improving patient care, and scientific progress towards an epilepsy cure.

ILAE Executive Committee



Malus usus est abolendus !!. There is currently a robust debate underway about the classification of seizures/epilepsies, as a prelude to a revision of the current schema. The ILAE executive committee invites debate and discussion, and all members are invited to contribute.

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).

6th Conference of Baltic Child Neurology Association, 13-16 June 2001

This will be held in Kaunas, Lithuania. For further information please contact Dr. Nerija Vaiciene/ Dr Milda Endziniene, Department of Neurology, Kaunas University of Medicine, Eiveniu 2, LT-3007 Kaunas, Lithuania.

Tel: +370 7 799 572
Tel/Fax: +370 7 330 423

e-mail: nerija.vaiciene@takas.lt OR nerv@kma.lt
Homepage: www.info.kma.lt.bcna

Focus on Epilepsy V1: Treatment of Epileptic Syndromes - From Molecular Targets to Quality of Life, Mont Tréblant, Quebec, Canada, 7-10 July 2001

The main theme of the conference is 'Treatment of Epilepsy Syndromes'. Further information may be obtained from the conference website, <http://www.total.net/~periplud/focus/>, or by contacting Periplus Convention Management.

Tel: +1 514 933 0502
Fax: +1 514 933 4513
e-mail: periplus@total.net

University of Munich Epilepsy Course, 23-25 June 2001

Contact: Dr Soheyl Noachtar
Tel: +49 7095 2685
Fax: +49 7095 6691

ASET Annual Convention, Renaissance Nashville Hotel, TN, USA, 15-18 August 2001

Contact: ASET +1 712 792 2978

www.awet@netins.net

The Fifth Etnean Epilepsy Workshop, St Thomas Convent in Linguaglossa on the Slopes of Mt. Etna near Taormina, Sicily, September 27-29 2001

The main themes of the workshop will be neuronal damage and neuroprotection in epilepsy, post-traumatic epilepsy, and sleep and epilepsy. For further information, please contact the Workshop's Secretary: Dr Antonio Pavane, EEG, Epilepsy Unit, Neurology Department, Ospedale Garibaldi, 95100 Catania, Italy.

Fax +39 095 31 21 52

e-mail: hsepa@tin.it

American Association of Electrodiagnostic Medicine Meeting, Albuquerque Convention Center, Albuquerque, NM, USA, 3-7 October 2001

Tel: +1 507 288 0100 Fax: +1 507 288 1225

American Epilepsy Society 55th Annual Meeting, Marriott Hotel and Pennsylvania Convention Center, Philadelphia, PA, USA, 30 November - 5 December 2001

Contact: Maria Rivera

Tel: +1 860 586 7505 Fax: +1 860 586 7550

e-mail: info@aesnet.org

13th Annual Meeting of the Portuguese Chapter, Coimbra, 15-16 March 2002

The main topics are: Epilepsy and Genetics, Pre-surgical Evaluation and Child Resistant Epilepsies.

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