

Epigrap^M

THE NEWSLETTER OF THE INTERNATIONAL LEAGUE AGAINST EPILEPSY

ISSUE 2 2000

Editorial

There is no better time than at the start of a Millennium for an organisation to look into its future. The leadership of the International League met recently to review its commitments, plans and desires for the future. The result of this meeting is a vision for our future; this is the subject of the Presidential Message by Pete Engel and also of an article by Walter Schaw. We would welcome the readership's view on the issues concerning the strategy issues relating to the League. Please write to the Editorial Office with any comments you may wish to make (the address is on the back page of this issue).

In this issue we also have news from the ILAE/IBE/WHO Global Campaign Against Epilepsy which is entering a new gear, with demonstration projects in several countries. We wish the Global Campaign every success in their efforts to reduce the burden which epilepsy brings to bear on all societies.

A contribution from India highlights some of the handicaps that people with epilepsy still encounter. Reports of interesting epilepsy initiatives in Argentina and France also feature in this issue. These types of initiative are to be welcomed and hopefully replicated in many more countries.

We learn of two projects to record the history of epilepsy; the setting up of a centralised archive in Bielefeld, and the creation of a Museum of Epilepsy in Kork/Kehl, Germany.

It came to our attention that a number of places seem to be having problems in receiving their copies of *Epigrap*. We are acutely aware how important it is to ensure that each member of ILAE worldwide gets their copy in good time. We are conducting a review into the way in which we distribute *Epigrap*. If you are experiencing problems or you know of any fellow members of the League who are encountering difficulties, please let us know by writing to the *Epigrap* office.

Ley Sander, Co-Editor

President's Message

Vision and Goals

Last year, the International League against Epilepsy celebrated its 90th anniversary. For most of these 90 years the League consisted of a small group of dedicated international leaders who fostered the development of local chapters, published our journal, *Epilepsia* and organised international congresses.



Although these efforts contributed importantly to the growth of the epilepsy movement worldwide, limited resources prevented more proactive projects on the part of the League itself. In recent years, however, the tremendous success of *Epilepsia* and of the regional, as well as international, congresses have provided substantial revenues. The ILAE Executive Committee and its commissions, often in close association with the International Bureau for Epilepsy have thereby been able to initiate numerous activities intended to improve conditions for people with epilepsy worldwide.

Growth

The last two administrative terms of the League have seen unprecedented growth in this regard, including:

- the publication of this newsletter and *Epilepsia Digest*
- the launch of the Global Campaign with IBE and WHO
- preparation for the joint ILAE/IBE portal website (intended to be the Internet one-stop shopping center for epilepsy)
- establishment of regional commissions and congresses for Asia and Oceania, Latin America, and Africa

- a wide variety of programs designed to foster basic research in epilepsy, search for epilepsy genes, delineate and alleviate the burden of epilepsy, support developing countries, and make improvements in diagnosis and treatment of epilepsy, including expansion of the application of surgical therapy.

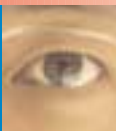
During this time, we have also slowly proceeded to make our administrative structure more professional by the establishment of an executive office and a financial office and the hiring of Dr. Walter Schaw, an expert in the administrative and maturational processes of international organizations, to help us move into what is clearly becoming a new phase in the evolution of the League.

Transition

In order to formally initiate a transition process, the first ILAE strategic planning meeting was held on April 15, 2000, in Basel, Switzerland (page 3). Invitees included the ILAE Executive Committee and commission chairs, as well as a number of other individuals who have provided important leadership on current ILAE projects. Almost all of those who were invited were able to attend. However, the list of participants in this strategic planning session highlights the fact that League activities are still dominated by Europe and

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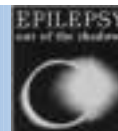
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North America. Although there are now more activities than ever before in Asia, Latin America and Africa, and all of these regions were represented at the strategic planning meeting, much more effort is now required to ensure that developing areas of the world receive full partnership in all of the affairs of the League.

Defining goals

The purpose of this first strategic planning meeting was to agree upon a vision statement for the ILAE, to delineate the specific long-term goals necessary to achieve our vision and to define specific objectives within each goal that can reasonably be achieved within three years. The next phase in the strategic planning process will be to decide upon, and initiate, specific action steps in order to realise each of the objectives. The strategic planning meeting was overwhelmingly successful, and the resultant first draft of the Vision Statement was then sent to all chapters for their comments. The Executive Committee of the League met on August 20 2000 in Venice, Italy, to further refine and approve this Vision Statement. The resultant draft will again be circulated to all the chapters and another strategic planning session, which will take place during the next meeting of the General Assembly at the International Congress in Buenos Aires in May 2001, will involve participation of delegates from all of our chapters.

The Vision

It was not an easy task to succinctly define "the vision," which would guide our actions over the foreseeable future, but everyone was ultimately very pleased with our final desire to "achieve a world in which no person's life is limited by epilepsy." It is anticipated that the ILAE will continue to work very closely with the IBE to pursue this vision, and participants from the IBE contributed importantly to a vision

statement that addressed the quality of life of people with epilepsy without the use of negative terminology.

Goal I

The first goal articulates the common motivational thread behind most of the League's activities since its inception. The objectives are not only to promote basic and clinical research, and to develop consensus guidelines for diagnosis and therapy, but also to assure that relevant information is readily available to everyone in the world who can use it, and more importantly, to create an interactive network of clinicians and basic scientists working in the field of epilepsy who will have access to this information, and be able to participate in the creation of new knowledge and the process of establishing standards of care. The ubiquity of the World Wide Web should ultimately make it possible for professionals everywhere, regardless of geographic location and local resources, to be a member of this interactive network.

Goals II and III

The second and third goals reflect the need to achieve positive results in the prevention and treatment of epilepsy worldwide. Specifically, they address the intention to ensure the existence of sufficient medical facilities with well-trained professionals to meet global needs, and also to ensure that all potential patients have access to these facilities and professionals. These are relatively new goals for the ILAE, and we have made major commitments to active efforts in this regard, together with the IBE and the WHO, under the auspices of the Global Campaign against Epilepsy. Now that the Global Campaign has been elevated to cabinet level by the WHO, we are assured of financial support from the WHO for this work, and the objectives outlined under these two goals represent areas in which the League anticipates tremendous growth over the next several years.

Goal IV

The fourth goal addresses the disabling behavioral consequences of epilepsy and is an area where the ILAE must now work closely with the IBE to establish mutually agreeable objectives and action steps that can be collaboratively undertaken.

Goal V

Finally, the fourth goal recognizes the extremely important need to create an administrative and financial infrastructure that will provide the resources and stability necessary to pursue our vision over the long term. An essential part of the transition of organizations such as ours from a small, modestly funded operation to a mature, geographically diverse international association with an active agenda and substantial financial means, is the establishment of a central administrative office with a professional staff who do not change with each new executive term. Until now, there has not been unanimity of opinion among members of the Executive Committee as to the need for a central administrative office, or how this administrative office should be constituted if we decide to create one. This was a major focus of the strategic planning meeting in Venice in August, and it is our hope to have very specific recommendations about this for the next Executive Committee, which takes office after the International Congress in Buenos Aires in May 2001.

We welcome your comments and suggestions regarding our Vision Statement and the strategic planning process.

Jerome Engel, Jr.
President

LIST OF PARTICIPANTS

V. Elving Anderson - United States
Giuliano Avanzini - Italy
Martin Brodie - United Kingdom
Esper Cavalheiro - Brazil
Hanneke DeBoer - Netherlands
Amadou Gallo Diop - Senegal
Charlotte Dravet - France
Jerome Engel Jr. - United States
Johan Falk-Pedersen - Norway
Natalio Fejerman - Argentina
Michael Hills - New Zealand

Richard Holmes - Ireland
Rajendra Kale - India
MC Maheshwari - India
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Facilitator - Walt Schaw, consultant

A SUMMARY OF THE STRATEGIC PLAN OF THE INTERNATIONAL LEAGUE AGAINST EPILEPSY

Basel, Switzerland, April 15, 2000

THE VISION

To achieve a world in which no person's life is limited by epilepsy.

GOAL I

To create an internationally understood and accepted knowledge base of epilepsy founded on an understanding of fundamental mechanisms.

Objective 1: Increase funding to promote research to bridge the gap between basic understanding and clinical application.

Objective 2: Develop consensus / guidelines for appropriate diagnostic and therapeutic standards.

Objective 3: Disseminate information globally using all available means.

Objective 4: Create an interactive global network of epileptologists to provide input and access to state-of-the-art knowledge. Promote collaboration.

GOAL II

To achieve universal primary and secondary prevention of epilepsy within acceptable ethical guidelines.

Objective 1: Identification of preventable causes and risk factors of epilepsy on a regional basis.

Objective 2: To develop regional plans for intervention.

GOAL III

To achieve access to appropriate medical care (accurate diagnoses and effective treatment).

Objective 1: Develop and begin a plan to provide (access to) all ILAE Chapters across all regions of the globe.

Objective 2: To support the advocacy efforts of ILAE Chapters and others with government and health agencies to ensure appropriate access to medical care for persons with epilepsy. (Reduce the treatment gap.)

Objective 3: Stimulate the development of epileptologists and epilepsy centres. (Identify role models.)

GOAL IV

To reduce the limitations encountered by persons with epilepsy and their families.

Objectives to be jointly developed by ILAE and IBE.

GOAL V

Create and maintain the administrative and financial infrastructure required to realise our objectives.

Objectives to be developed by the ILAE Executive Committee, including staffing and financial plans.

A Vision for the Future

A report of the ILAE Strategic Planning Meeting and A Process Called "Visioning"

By **Walter A. Schaw, Ph.D., CAE, SPM, Facilitator**

"What do we want the world of epilepsy to look like, to be like, some ten and twenty years from now?" That challenge opened an intense day of developing the Strategic Vision of ILAE in Basel, Switzerland, on April 15, 2000. Charged with daring to dream and then putting substance to that dream was a broadly representative group of 29 leaders drawn from ILAE, IBE, and WHO and some 19 countries across six continents.

The dramatic product of that day is reported in the President's Message of this issue of *Epigraph*. However, I would like to review the process of how these ideas and beliefs came about - a process which I believe gives authority to the priorities of the Vision on behalf of all of the ILAE.

We followed a process that I have been facilitating with many diverse groups since 1978. It relied on the exchange of ideas between small groups of fewer than seven persons and began by reaching a strong consensus of the overall group in defining the Vision of our dreams.

Once a Vision was adopted, the next step was to define Goals, priority outcomes which must be

realized if the Vision is to move from dream to reality. Third, with Goals in place, Objectives or near-term (three-year) strategies were added next to advance the new Goals as ILAE priorities. Objectives are specific plans which describe the work to be done, who will do it, what the cost will be, and what measurable results should be realistically expected.

A fourth element, Action Steps, identified what can be done this fiscal year within existing programs and budgets to begin advancing the Objectives. These will be expanded, appropriately, by the ILAE Executive Committee at a retreat of the group in Venice on August 20th.

Also an important part of the process was a Consensus Discipline. We worked with five small groups of fewer than seven persons to develop ideas at each step of the exercise (Vision, Goals, etc.) Any idea had to have unanimous acceptance within the small group before it could be presented when the overall group reassembled. The test of the small group before reaching a conclusion was "have all of the voices been heard." One of the values of

small groups is that the quieter persons, those who hesitate to speak up in large groups, often offer the highest quality ideas.

In the ILAE meeting, synergy occurred and the process "ignited" as small groups presented very similar ideas to the overall group. These ideas were readily combined into statements that could be (and were) adopted by most participants. What emerged was one of the most powerful strategic planning documents of my experience.

Every "Visioning" exercise I do is a learning experience. So too, the ILAE strategic planning meeting gave me new insights into the process. I believe that much of the power of the document was drawn from the diversity of the participants, representing a wide spectrum that enriched us all.

That diversity is a great strength of ILAE. That is the key to achieving your dreams.

"Cherish your dreams, they are the children of your soul."

The Rumi, 13th Century

24th International Epilepsy Congress

Buenos Aires, Argentina - May 13-18, 2001



XV International Congress of Clinical Neurophysiology

Buenos Aires, Argentina - May 16-20, 2001



It is obviously clear that the fact that the ILAE and the IBE are organising their meeting together has largely contributed to the increasing success of the International Epilepsy Congresses, in terms of scientific achievements and number of attendees.

This time, a new and interesting fact is added as a result of the decision to hold part of our meeting together with the XV International Congress of Clinical Neurophysiology.

As usual, the most important issues and significant recent advances in areas such as Genetics, Neurobiology and Disorders of Cortical Development disclosed through new techniques in brain imaging, are balanced with several other items. The emphasis on providing a better quality of life for people with epilepsy, together with prevention of this disease and the need to get epilepsy "out of the shadows," are subjects of major importance in the new Millennium.

However, there will be more than just science: we are planning daily non-parallel sessions on how to dance the "tango".

The time to visit or re-visit these latitudes is near. We are sure that Argentina, the City of Buenos Aires, and the friendly people of this country will ensure you enjoy your stay and will contribute to the success of this Congress.

Natalio Fejerman
Chairman 24 IEC

24th INTERNATIONAL EPILEPSY CONGRESS

Preliminary Scientific Programme

Main Sessions and Post Main Sessions

- Neurobiology of Human Epilepsy Tissue and Relevant Animal Models
- Subtle Manifestations of Psychopathology in Epilepsy
- Advances in the Clinical and Molecular Genetics of the Epilepsies
- Public Health Issues and Prevention of Epilepsy
- Comprehensive Care in 2001
- Epilepsy in Schools Years

Parallel Sessions

- Pediatric epileptology
- Genetics: A New Frontier in Pharmacology of Epilepsy
- The Puzzling Genetics of the Generalized Epilepsies
- Status Epilepticus in Adults and Children
- A Lifetime Experience in the Treatment of Epilepsy in Children
- Psychological Approaches to Seizure Control
- Febrile Seizures: a Model of Genetic and Acquired Interaction
- Guidelines for AED Therapy
- Visually Induced Seizures.
- Living with Epilepsy
- Epilepsy and the School Years: Tools for the Teacher
- Is it Possible to Prevent Intractability
- Economic Aspects of Epilepsy
- Mortality in People with Epilepsy
- Epilepsy Surgery in Children in Latin America

- Clinical Epileptology of Disorders of Cortical Development
- Quantitative Approaches to Studies of Human Epileptic Tissue
- Seizure Prediction: Is it Feasible in Real Time?
- Long-term monitoring for patients with refractory epilepsy
- Epilepsy Risks and Insurability
- Critical Interpretation of AED Trials
- Epilepsy and Intellectual Disability

Breakfast Seminars

- Genetics of the Epilepsies - a Guide for the Perplexed
- A Center for the Clinical and Neuro Biological Study of Human Epilepsies
- Brain Damage in Status
- Learning Disorders and Epilepsy
- French National Network of Epilepsy Surgery
- Educational Issues for School Children in South America

Joint Session 1:

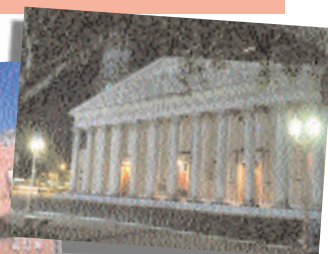
Disorders of Cortical Development
Free Communications, Posters Discussion,
Video Cases

Young Investigator Award, Young Researchers Course

Sponsored Satellite Symposia

Workshop on Neurobiology of Epilepsy (WONOEP)

Workshop on Neuroimaging in Epilepsy: A Practical Course



Initiatives from around the Globe . . .

ARGENTINA – EPILEPSY WEEK

From 26th-30th June 2000 the Argentinean Epilepsy Week was held. It was organised by the Municipal Center of Epilepsy within the “Ramos Mejía” Hospital, University of Buenos Aires, CONICET and Fundepi (A Foundation of Epilepsy), with support of the Health Secretary of Buenos Aires, the Epilepsy Group of the Argentinian Neurological Society (SNA) and the Argentinian branch of the International League Against Epilepsy (LICE). The main objective of the week was to highlight discrimination and fight against epilepsy. The activities were planned to inform the population about the disease and different treatment possibilities.

All the activities were free. They took place on two different levels: the hospital and the media. With regard to hospital activity the population was informed about the creation of a network between public hospital services, including a free telephone line which was installed, answered by trained patients from self-help groups. Training meetings were organised by health professionals for the general population and epilepsy patients alike. We also organised workshops for patients, co-ordinated by patients. Conferences and lectures were given on certain issues surrounding epilepsy, carried out with the support of professionals and famous

celebrities. An informative leaflet was widely distributed. The media was fully involved from posters in the streets to spots on TV, radio and cinema, co-ordinated by a patient at the centre, Andrés Firbank. The result was impressive. We received more than two hundred calls daily and around 150 people attended the activities each day. We consider we have achieved our goal, the issue of Epilepsy has been incorporated into our society and echoing the Media's motto, “Anyone can suffer from epilepsy, you only have to treat it”- we believe, a big step was made to educate people about epilepsy.

Dr Silvia Kochen

FRANCE – NATIONAL EPILEPSY DAY

Within the framework of the Global Campaign, ‘Epilepsy out of the Shadows’ launched in 1997 by the ILAE, the IBE and the WHO, the five organisations which deal with epilepsy in France decided to jointly organise a National Epilepsy Day in order to inform the general public about the condition and to improve the image of epilepsy patients throughout France.

This National Epilepsy Day will be held on November, 18, 2000.

Members of the following organizations have established the objectives of the campaign:

- FLAE, *French chapter of ILAE*
- AISPACE, *French chapter of IBE*,
- BFE, *Bureau français de l'Epilepsie*,
- ARPEIJE, *Association pour la Recherche pour l'Education et l'Insertion des Jeunes Epileptiques*,
- FFRE, *Fondation Française pour la Recherche sur l'Epilepsie*,

The objectives are:

- to inform and increase knowledge and awareness of public and patients about epilepsy, about what it is and what it is not

- to stress the medical, social, psychological and economical aspects
- to alert the official bodies and media to the problems of patients with epilepsy
- to gain a better understanding and acceptance of people with epilepsy by employers and colleagues at work
- to change the image of epilepsy and to allow patients and their families to speak up and to have their right place in society.

There will be no fundraising.

The activities will be mainly focused at a local and regional level, organised by by various members of the associations, each following a common strategy.

Thirteen cities and towns in different regions have been chosen. In each location there will be a team of ‘non-experts’ who will take charge of the campaign, aided by at least one epileptologist and a member of the French league .

There will be a full day meeting, in a public place, which will bring together patients, families, professionals and the public. Leaflets, reviews and informative material published by the different associations will be available. There will also be input from professionals; progress reports of advances

in clinical and fundamental research, opportunities for participants to have their say and conferences led by specialists in their respective fields. In addition there will be

- posters in various places of the town
- interviews with various regional public bodies about the structures for professional training, handicapped people, etc.
- articles in regional newspapers
- programs on radio and television

Moreover, a *Round Table* between several high level personalities in research, sociology, psychology and economics, will be organised in Paris the day before, with the participation of a member of the International Global Campaign.

The National Day will be announced at the Journées Françaises de l'Epilepsie which will take place the week before (November 11-14 at Annecy), through the media and Internet.

We hope that on **November 18**, all over France, people can learn about epilepsy, ask questions and receive quality responses, thereby acquiring greater knowledge about the condition. We hope that this first National Epilepsy Day will become an annual event.

Dr Charlotte Dravet

The Global Campaign against Epilepsy

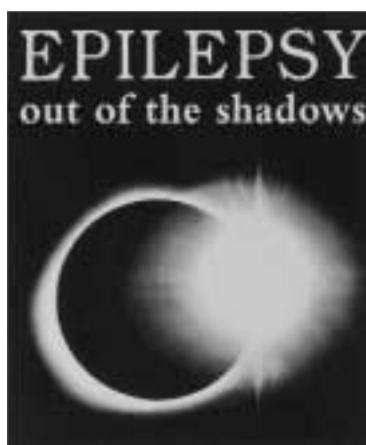
An Update on the progress of the campaign

The Secretariat of the Campaign, consisting of Prof. E.H. Reynolds (ILAE, UK), Dr. L.L. Prilipko (WHO, Switzerland) and myself (IBE, The Netherlands) as the chair of the Executive Board of the Campaign met twice in Geneva, Switzerland, at the WHO Headquarters, once in London, UK, once in Basle Switzerland, together with the Executive Board of the Campaign at the time of the meetings of the Executive Committees of IBE and ILAE and finally once in Heemstede, The Netherlands.

At the end of 1999, the Cabinet Paper on Epilepsy had been approved by the WHO Cabinet, which marked a number of the activities this year.

According to the Cabinet Paper, the strategy of the Campaign includes two parallel and simultaneous tracks:

1. to provide a general platform of awareness
 - a. to intensify and boost the Campaign in the year 2000 with the participation of the Director-General of WHO, WHO Regional Directors and the Presidents of the relevant NGO's
 - b. to organise regional conferences on public health aspects of epilepsy in the six WHO Regions, including a Declaration on Epilepsy, based on the European model
2. to assist Departments of Health in the development of national programmes on epilepsy
 - a. to provide information and support national initiatives under the Campaign
 - b. to initiate Demonstration Projects



Many activities arose from the two initiatives. Much time was spent on discussing the intensification of the Campaign, which soon became known as the 2nd Phase Launch, with a new and more ambitious goal: to improve health care services, treatment, prevention and social acceptance world wide. The original idea was to organise the 2nd Phase Launch during this year, but due to internal re-organisations

within WHO this proved to be impossible, and it is now very likely that the Launch will take place in February of 2001. Obviously, as soon as the date is known, all chapters and other relations of IBE and ILAE will be informed. They will then also be invited to join in this important event.

The first Regional Conference took place in Heidelberg, Germany in October 1998. Since then, another such conference took place in Dakar, Senegal in May of this year. Here also a Regional Declaration was developed and unanimously agreed by all present, which consisted of professionals working in the field of epilepsy, representatives from the government, officials from universities, etc. Another regional conference is due to take place in Santiago de Chile, preceding the Latin American Conference in September, one in New Delhi, India in November, preceding the Asian and Oceanian Congress and finally one more will take place in the USA, Los Angeles, prior to the Conference of the American Epilepsy Society. Declarations are already being developed for each of these occasions. More Regional Conferences will be initiated next year.

At present over 40 countries world-wide are organising or have organised activities under the auspices of the Global Campaign and more do so all the time.

The Secretariat of the Campaign produced the first annual report and a brochure on the Campaign to inform interested parties better about the goals and activities. A few copies have been sent to all chapters but more can be ordered from the IBE office in Heemstede.

Another extremely important activity under the Campaign is the development of the Demonstration Projects. At present one such project is on the way in China, preparations are being made for projects in Africa (Zimbabwe and Senegal) and in Latin America. All in all these projects made a slow start, if only because manuals needed to be developed, definitions to be agreed upon and outcome measures to be defined. Needless to say, you will hear much more about these projects in the near future.

All in all these were a very busy six months and it does not look as if the second half of this year is going to be more quiet with three regional conferences due to take place, the preliminary work for starting the Demonstration Projects to be finalised and the preparations for the 2nd Phase Launch in full swing.

You will hear more about all of this soon!

**Hanneke M. de Boer, Chair Executive Board
ILAE/IBE/WHO Campaign against Epilepsy**

A Tribute - The Father of Turkish Epileptology



Kenan Tükel

Kenan Tükel, born in 1915, graduated from the Medical Faculty of Istanbul University and began his residency as a Neuropsychiatrist. He completed his residency and went to Paris to work with Dr. Fischgold in 1947. Between 1950 and 1952 Tükel went to Montreal and worked with Dr. Jasper and Dr. Penfield at MNI as a fellow.

In Dr. Frederick Andermann's article written in memory of Jasper (Epilepsia vol 41, 1 May 2000) Kenan Tükel is referred to as a member of the multidisciplinary core group constituted in MNI. 'The electroencephalogram in parasagittal lesions' written by Tükel and Jasper in *Electroencephalography and Clinical Neurophysiology Journal* in 1952, was not only a very important article in terms of bilateral secondary synchrony but also one of the first and the most cited articles in epilepsy in the world.

Tükel worked at the Children's Hospital in Montreal where he founded an EEG lab. In 1952 in an article he wrote with his wife Dr. Maide Tükel, they described their clinical observations of the drug 'Dormison' used in children to record their sleep EEGs. The significance of this article lies in the impossibility of recording EEGs and especially sleep EEGs in children in those days. He was also the first epileptologist to found an EEG lab in Turkey and this lab is dedicated to him.

Kenan Tükel passed away in 1993. He was a prominent physician, whose memory will be treasured by epileptologists in Turkey and worldwide.

Dr Candan Gurses

From Darkness into Light: an Indian experience



Indian wedding ceremony

Now the story can be told. Only two decades ago an horrendous Indian law was enacted which specifically prohibited a legally valid marriage for a person with epilepsy, leaving many women with the sword of Damocles, in the form of divorce, hanging over their heads. This pernicious law has now been abolished.

The story began in 1986, when we first learnt of the existence of this law. Shocked to the core, we sent repeated petitions to successive Prime Ministers and their colleagues in the Government of India. Begun in 1987, this effort continued for the next ten years, but with no worthwhile result. Finally, in September 1996 the Indian Epilepsy Association (IEA), Bangalore Chapter, represented by myself, with Dr Ramamurthi and Dr Eddie Bharucha – all of us founder members of the IEA in 1971. We filed a Public Interest Litigation against the Federal Government in the Supreme Court of India. The legal basis was that the law infringed on the rights guaranteed under the Constitution, that is, Equality before the Law and a Right to Live (with Dignity). During the hearing, the Solicitor-General of India stated in the court that the respondent was contemplating certain changes in the marriage

laws under challenge. Accordingly, a fortnight later a bill was introduced to Parliament, but could not be pursued due to political instability.

After the present government was formed in October 1999, intense lobbying by Mr Govindh Bharathan, our lawyer and Dr Arjun Das gave a kick-start to the process. The bill de-linking epilepsy and divorce was passed in both houses of Parliament and ten days later the assent of the President was obtained, rendering the new Act operative with immediate effect – all in one month. The legal shackles binding epilepsy sufferers were at last broken, the ghost exorcised and human dignity restored.

Dismay and frustration had been our companions throughout these 12 years. We also learnt the virtues of patience, perseverance and tact. The central office of the ILAE and

the IBE, then in Heemstede, helped us to gather material from their chapters on the position of epilepsy and the law in their own countries. The National Human Rights Commission and Women's Welfare organisations in India also chipped in. This was a combined effort towards a common objective of setting right a wrong, in which the present government played a pivotal role. Indian society owes all of them grateful thanks.

We in the IEA are all on 'cloud nine', not without justification, we hope, and would like our colleagues in the ILAE, the IBE and their chapters worldwide to share our happiness. Can we die in peace? Clearly not. We have other unfinished business, but that is a different story

Dr K. S. Mani

Another Searchlight on History?

The electronic age creates a risk that changes will happen so rapidly that the original course in no time is out of sight. The more reason to abstract the past and visualise developments and intentions of where to go in future. The ILAE has appointed a taskforce to advise the executive which materials should be conserved for future generations and how best to make these accessible. This resulted in a decision to store archives in a central place (at the Epilepsy Centre Bethel in Bielefeld Germany).

A history of the ILAE 1909-1999 has also been published in booklet form and is available from the office of the Secretary General; copies were presented to participants in the 23rd International Epilepsy Congress in Prague in 1999. The history task force also recommended establishing a Museum for the History of Epileptology.

However, there is no need to re-invent the wheel; in 1998 Dr HansJorg Schneble, working at the Epilepsy centre Kork/Kehl came to an agreement with the municipality of Kork to make five rooms of the Korker



Artisans Museum available for an Epilepsy Museum. Dr Schneble has managed to bring together a most interesting collection, which is presented in a well-organised and instructive way. Lack of space only permits an 'appetiser' picture to accompany this article. More can be seen on the internet at <http://www.epilepsiemuseum.de> (note **epilepsie** not epilepsy!) As Kork/Kehl is a city across the Rhine from Strasbourg and has the European Parliament only some 25 km away, it is an appropriate place for an international undertaking.

The taskforce invites anyone who wishes to donate materials of historical interest to the Museum for Epileptology either to contact:

The Secretary General of the ILAE,

or

Dr HansJorg Schneble Epilepsiezentrum Kork,
Landstrasse 1, 77694 Kehl-Kork;
Tel. +49 785 184230;
Fax + 49 785 184553;

e-mail hschneble@epilepsiezentrum.de

TURKEY



The National Epilepsy Congress organised by the Turkish Epilepsy Society, was held from 7th-10th June 2000. It proved to be very successful and rewarding. A course supported by EUREPA on basic mechanisms was organised on the first day of the Congress.

From June 5-6th The Turkish Epilepsy Society Education Committee gave a seminar including a video display (examples of common seizure types) to primary school teachers from all over

Istanbul. After the seminar, a few students with absence seizures were referred to us and they were diagnosed as having childhood absence epilepsy. Treatment was initiated immediately. This was perhaps the most satisfactory consequence of the seminar for us physicians.

Dr. Candan Gurses

UNITED KINGDOM



Simon Shorvon writes: "I am very keen to have any information about the historical

aspects of *status epilepticus*, as I am writing the second edition of my *status epilepticus* book. Information will be gratefully received. Please contact:
Professor Simon Shorvon, 6th Floor, Department of Clinical Neurology, Institute of Neurology, Queen Square, London WC1N 3BG, UK.

e-mail: s.shorvon@ion.ucl.ac.uk

Fax: +00 44 20 7837 2062

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.

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

For further information please contact: Dr Satish Jain, Secretary General, Dept. of Neurology, Neurosciences Centre, All India Institute of Medical Sciences, New Delhi-110 029, India.

Tel: +91 11 659 4210/656 9007. Fax: +91 11 652 1086/686/2663

e-mail: satjain55@hotmail.com

54th Annual Meeting of the American Epilepsy Society, Century Plaza Hotel and Tower, Los Angeles, CA, 1-6 December 2000

The Scientific Program, chaired by Dr William Theodore, will consist of three symposia, over 80 poster sessions and 140 platform presentations, special interest group meetings, participatory round-tables, the Lennox Lecturer and Awardee, awards luncheon, exhibits, and the business meeting.

Web site:

<http://www.aesnet.org/conference/index.htm>

International Symposium on the West Syndrome and Related Infantile Epileptic Encephalopathies (ISWS), The Yakoi Memorial Hall, Tokyo Women's Medical University, Shinjuku-ku, Tokyo, Japan, 10-11 February 2001

The main theme of this symposium is the better understanding of etiopathogenesis and exploration of new treatment strategies in various intractable epileptic encephalopathies with suppression burst (Ohtahura syndrome), and severe myoclonic epilepsy in infancy (Dravet), in particular. Official language: English.

Abstract deadline: 31 October 2000

Contact: Yukio Fukuyama, MD
Secretariat, ISWS
c/o Child Neurology Institute
Samban-cho, TY Plaza, 5F1.
24 Samban-cho, Chiyoda-ku
Tokyo, 102-0075, Japan

Tel: +81 3 3238 1580

Fax: +81 3 3238 1502

e-mail yfukuyam@sc4.so-net.ne.jp

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).

Workshop on Neurobiology of Epilepsy (WONOEP), Iguazu, Brazil, May 8-10, 2001:

WONOEP VI — an official ILAE-sponsored satellite meeting devoted to the basic science of Epilepsy — will be held May 8-10, 2001 at the Tropical Hotel in Iguazu, Brazil, immediately before the 24th International Epilepsy Congress in Buenos Aires, Argentina. WONOEP VI will feature a workshop format emphasizing open discussions, with a broad theme of "Ictogenesis and Epileptogenesis". The number of participants in WONOEP is limited. All epilepsy researchers are invited to apply by emailing, before November 1, a one-page abstract describing the research they would like to present to: wasterla@ucla.edu.

Contact: Esper Cavalheiro,
Escola Paulista de Medicina, Rua Botucato 740,
CEP 04023-900, Sao Paulo, Brazil, or

Claude Wasterlain,
West LA VA Medical Center (127),
11301 Wilshire Blvd, Los Angeles, CA 90073, USA

Fax: +1 818 895 5801

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 VI-Treatment of Epileptic Syndromes: From Molecular Targets to Quality of Life, July 7-10 2001

The main theme of the conference is the treatment of epileptic syndromes.

Scientific organisers: Dr Massimo Avoli of McGill University, Dr Michael Rogawski of the National Institute of Health, Dr Giuliano Avanzini of Istituto Neurologico "C.Besta", and Dr Claude Wasterlain of University of California at Los Angeles.

You can get all the details from our conference information center: <http://www.total.net/-periplus/focus> or contact Periplus Convention Management:

Tel: +1 514 933 0502

Fax: +1 514 933 4513

e-mail periplus@total.net

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