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ILAE Special Article

President's Report (1993–1997)

The 4-year (1993–1997) term of the ILAE Executive is now completed at this, the 22nd International Epilepsy Congress in Dublin. This final report should be read in conjunction with my address to the ILAE General Assembly in Oslo in July 1993 (*Epilepsia* 1994;35:713–4) and also my mid-term report after the 1995 Sydney Congress (*Epilepsia* 1996;37:221–3).

Our constitution demands that we advance and disseminate knowledge about epilepsy; promote research, education, and training; and improve services and care for patients, especially by prevention, diagnosis, and treatment. In Oslo I noted that knowledge about epilepsy is advancing but that its application to people with epilepsy has been very limited. Progress in education, training, services, and care has been slow and patchy in the developed world and almost nonexistent in the developing world. Very few departments of health give much or any consideration to the problems of epilepsy, despite the scale of the problem.

To begin to address these universal problems in a global, international, collective manner, my first objective was to improve the lines of communication within the League and to make it a more visible, cohesive, and effective organization at a time of rapid growth.

COMMUNICATION AND GROWTH

As described in my mid-term report, a staffed office for the Secretary-General, Professor Peter Wolf, was established in Bielefeld, Germany, for the first time in the League's long history since its birth in 1909. I am very

Chapters of the ILAE, July 1997

grateful to Peter Wolf and his assistant, Mrs. Irene Kujath, for establishing and improving communication with the Chapters, processing new applications, and coordinating the growth of the ILAE. The number of chapters has increased from 40 in 1993 to 62 4 years later in 1997, an unprecedented growth rate of >50%. Although half the chapters are in Europe, we now have chapters on every continent, and the world map of ILAE is not unlike that of the British Empire, of which it was said, "The sun never sets." We are now a truly global organization.

Since 1994 the office has been responsible for producing for the first time ILAE Annual Reports in each of the last 3 years. Another new initiative has been the establishment of the League's first newsletter, *Epigraph*, under the editorship of Professor Simon Shorvon. *Epigraph* has been produced twice yearly since its inception in 1994 and is sent free of charge to all ILAE members, thanks to sponsorship. Most chapters have now submitted their membership lists, and the newsletter currently reaches over 12,000 members.

Under our new editor, Professor Tim Pedley, our official journal, *Epilepsia*, expanded to a monthly journal in January 1995. Manuscript submissions have increased by 20%, and standards have risen with an impact factor of 2.340 (seventeenth of 98 neuroscience journals). Submissions and acceptances have slowly become more global, although still dominated by the developed countries, who provide most of the 4,000 plus subscribers, at least in part because of the high cost of the journal. For these reasons, a pilot project of a low-cost quarterly, Epilepsia Digest, has been established in India since 1996 under the editorship of Dr. Rajendra Kale, who liaises closely with Tim Pedley. If this project is successful, we hope to extend the scheme to other parts of the developing world. At the same time, to make Epilepsia more accessible to a wider audience, the subscription rates have been greatly reduced under a new 5-year contract with the publishers, Lippincott Williams & Wilkins.

Another development I encouraged is the application of public-relations techniques and advice from Harrison Cowley Public Relations in London to our organization, and especially to the ILAE/IBE/WHO Global Campaign (vide infra) to increase the profile of ILAE as well as of epilepsy. The League now has its own portable display stand for use not only at epilepsy congresses but, most important, at neurologic and other events.

Another idea is gradually taking shape under a joint ILAE/IBE Working Party, chaired by our Treasurer, Professor Pete Engel: a joint ILAE/IBE website, possibly in collaboration with the *British Medical Journal*, for whom Rajendra Kale is a consulting editor. This will probably be established in 1998. I also am grateful to Professor Harry Meinardi for beginning the difficult task of establishing an ILAE archives, currently in The Netherlands.

FINANCES

Thanks to the considerable efforts of our Treasurer, Pete Engel, the League's finances have never been in a more healthy state. New procedures for the collection and acknowledgment of chapter dues, new accounting systems, and investment advice have reorganised and streamlined the finances. Furthermore, although ILAE activity and expenses have grown every year, the latter have never exceeded income, which is mainly from *Epilepsia*, Congresses, Commission grants, and chapter dues. As a result, ILAE resources have grown each year, and the new Executive will begin its work in a sound financial state.

REGIONAL DEVELOPMENTS

With the growth and globalization of ILAE, there have been important regional developments.

A unique regional structure with 31 chapters has been developed and implemented in Europe. This is described in the second issue of Epigraph for 1997, and it may serve as a model for other regions. Each chapter is represented by one member in a European Advisory Council, which has been chaired by Peter Wolf. The Council elected five of its members to serve on a new European Commission. This is a novel development, as constitutionally and traditionally members of all Commissions have always been appointed by the President. In this Regional Commission, however, the President appoints only two further members and chooses the Chairman. The European Commission receives its brief from the President but also receives advice from the European Advisory Council. The Commission reports to both the ILAE Executive and to the European Advisory Council.

The European Commission, under the chairmanship of Simon Shorvon, has produced a report on standard of epilepsy care in Europe and guidelines for ILAE European Congresses. It has stimulated the formation of a European Academy for Education. The first European Congress of ILAE was held in Oporto in September 1994, and the second, in The Hague in September 1996. The third will be held in Warsaw in May 1998, and the fourth will be in Florence in the year 2000.

At the first Asian and Oceanian Epilepsy Organisation (AOEO) Congress in Seoul in September 1996, I con-

vened a meeting of representatives of Asian and Oceanian countries irrespective of whether they had a League chapter. With the agreement of this group, I subsequently appointed a Commission on Asian and Oceanian Affairs under the Chairmanship of Professor Masakazu Seino, former ILAE Executive member and Treasurer. It is also hoped that the AOEO will evolve into the equivalent of the European Advisory Council as more chapters are developed in the region. The second Asian and Oceanian Epilepsy Congress will be held in Taiwan in November 1998.

Preparatory work has been under way to establish a similar regional structure for Latin America, after the seventh Pan American Epilepsy Congress in Buenos Aires in September 1997. This and other regional developments will be the responsibility of our new President and Executive.

I was pleased to attend the first Pan Arab Congress on Epilepsy in Riyadh in March 1997. Other informal regional groupings include those of the Mediterranean and Pacific Rim countries.

COMMISSIONS

Much of the work of ILAE is undertaken by international Commissions established by the President, after consultation. I set up 15 Commissions and two Subcommissions, which are listed together with the Chairpersons in my mid-term report, and are described in more detail in the ILAE Annual Reports. It was my policy to work closely with the Chairperson in establishing the objectives and membership of each Commission. Many Commissions have reported their activities and the outcome of their work in the Annual Reports of ILAE, in *Epigraph*, and in *Epilepsia*, and further reports are in the pipeline. I am very grateful to so many colleagues around the world who have voluntarily given so much of their time and expertise in the service of ILAE.

The Chairpersons of each Commission, together with the Executive Committee, constitute the Long-Range Planning Committee of ILAE. The Long-Range Planning Committee met in London in November 1994 and in San Francisco in December 1996 to review collectively the work of the Commissions and the implications for the future planning of the ILAE.

INTERNATIONAL BUREAU FOR EPILEPSY (IBE)

The ILAE works closely with its sister lay organization, the IBE. This is reflected in interlocking Executive Committees and also in Joint Executive Committee meetings. Relations between the League and the Bureau have been excellent in the last 4 years, and I am grateful to Hanneke de Boer (President) and Michael Hills (Secretary-General) for their support for the work of the

League. Peter Wolf and I have been happy to reciprocate for the Bureau.

Examples of our collaboration are

- 1. The joint biennial international Congresses at which participation has doubled to nearly 5,000 delegates between Oslo in 1993 and Dublin in 1997
- 2. The plans for a joint website.
- 3. The ILAE/IBE/WHO Global Campaign.

ILAE/IBE/WHO GLOBAL CAMPAIGN

Both ILAE and IBE are nongovernmental organizations affiliated with WHO. In view of the political neglect and low profile of epilepsy referred to in my inaugural report and in this report, I proposed to WHO in January 1996 a global initiative for this worldwide problem. After a meeting and workshop of the Developing Countries Commission in Geneva in June 1996, the WHO agreed in principle to this idea.

The Global Campaign Against Epilepsy is a joint initiative of three worldwide organizations, the ILAE (professional), the IBE (lay), and the WHO (political). It was formally launched in Geneva on June 19th 1997 and Dublin on July 3rd 1997.

Mission

To improve the acceptability, treatment, services, and prevention of epilepsy worldwide.

Objectives

- 1. To increase public and professional awareness of epilepsy as a universal, treatable brain disorder.
- 2. To raise epilepsy on to a new plane of acceptability in the public domain.
- 3. To promote public and professional education about epilepsy.
- 4. To identify the needs of people with epilepsy on a national and regional basis.
- 5. To encourage governments and departments of health to address the needs of people with epilepsy, including awareness, education, diagnosis, treatment, care, services, and prevention.

Programmes

To achieve these objectives, the Campaign is developing two parallel and simultaneous programs over the next 4 years:

- 1. A global public-awareness programme.
- 2. A programme of practical assistance to governments and departments of health working through the worldwide network of ILAE/IBE Chapters and Epilepsy Organizations and the WHO network. This will take the form of encouragement, guidance, advice, information, and assistance, especially in identifying the needs of people with epilepsy, and in the education and training of public and professionals.

Individual chapters, countries, and departments of health will be encouraged to develop their own national campaigns, depending on local needs and resources.

The Global Campaign is being developed and monitored by an International Consultative and Collaborative Committee made up of members of the three organizations and of which I am currently chairman.

CONCLUSION

The ILAE has grown at an unprecedented rate in the last 4 years and is now a truly global organization necessitating the evolution of regional structures. The organization is now more cohesive and has improved its lines of communication with its chapters and members and with its external target audiences. Its finances have been streamlined and resources increased. Its activities have enlarged through a wide range of Commissions, and for the first time, it is undertaking global and political initiatives in collaboration with other relevant organizations to address the neglect of the universal problem of epilepsy.

I am very grateful to all my colleagues on the Executive and in the Commissions and all who have supported the work of ILAE in the last 4 years, including our colleagues in IBE. The new elections have resulted in global representation on the Executive, and I wish the new President, Pete Engel, and the Executive every success in carrying forward the work of ILAE on behalf of people with epilepsy as we approach the millennium.

Edward Reynolds President 1993–1997 Institute of Epileptology King's College Hospital London

(Based on an address to the ILAE General Assembly, Dublin, July 3, 1997.)