

Introduction

- ◆ Professional organizations refer to the organizations of physicians and other health professionals in the field of patient care, research or education in epilepsy and whose

principal concern is with the problems of epilepsy; such organizations are usually nongovernmental.

Salient findings

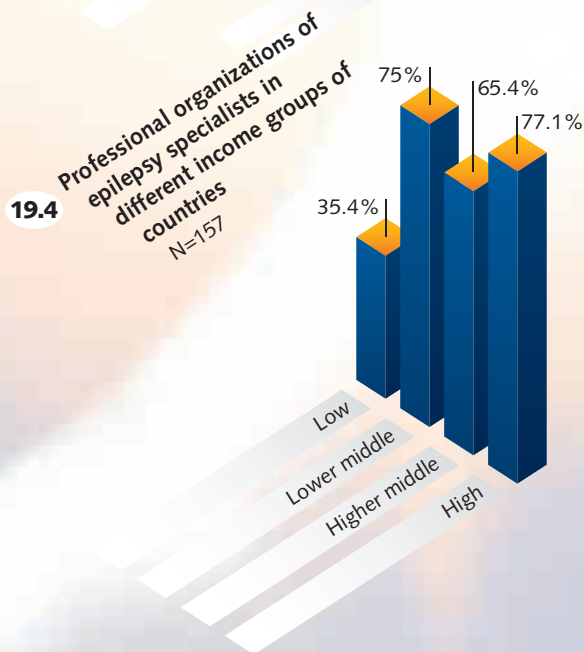
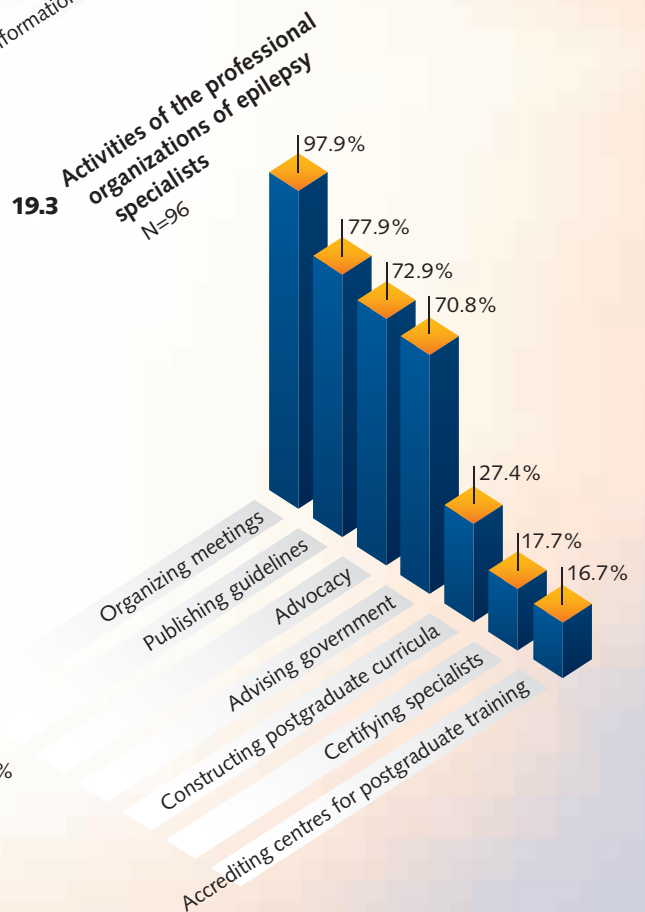
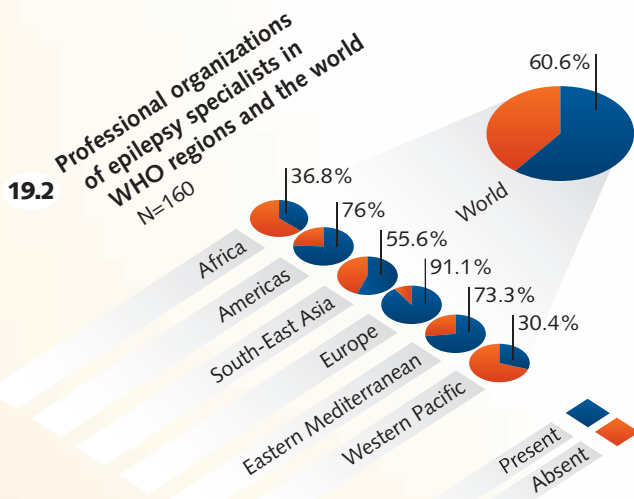
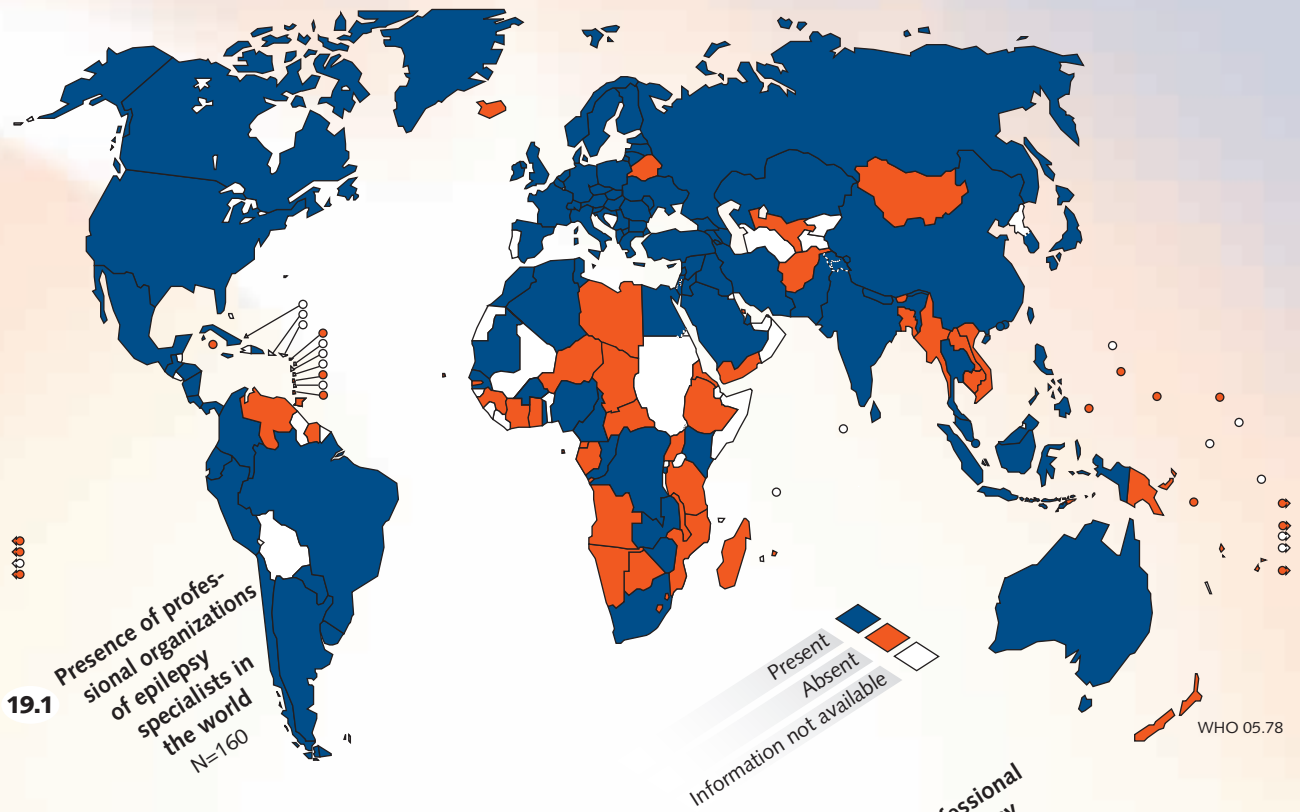
- ◆ A professional organization of epilepsy specialists exists in 60.6% of the responding countries.
- ◆ Of the responding countries, 69.6% and 63.2% in the Western Pacific and Africa, respectively, do not have a professional organization of epilepsy specialists, compared with 44.4% in South-East Asia, 26.7% in the Eastern Mediterranean, 24% in the Americas, and 8.9% in Europe.
- ◆ A median number of 75 (interquartile range 30–213) professionals are members of the organization in the responding countries. The median number of professionals who are members of organizations per 100 000 population is 0.75 (0.25–2.08).
- ◆ The median number of professionals per 100 000 population who are members of an organization of epilepsy specialists is 0.17 in South-East Asia and Africa, and 0.31, 0.33 and 0.35 in the Western Pacific, the Eastern Mediterranean and the Americas, respectively, compared with 2.15 in Europe.
- ◆ Professional organizations of epilepsy specialists do not exist in 64.6% of low-income countries compared with 22.9% of high-income countries. Also, the median number of professionals per 100 000 population who are members of an organization of epilepsy specialists varies across different income groups of countries (0.19 in low-income countries, compared with 1.83 in high-income countries).
- ◆ The professional organizations of epilepsy specialists are involved in various activities including: organizing professional meetings and conferences on epilepsy (97.9% of responding countries), publishing guidelines and recommendations on epilepsy (77.9%), advocacy on epilepsy-related issues (72.9%), advising government (70.8%), constructing curricula for postgraduate training in epileptology (27.4%), recognizing or certifying specialists in epileptology (17.7%) and accrediting epilepsy centres for postgraduate training in epileptology (16.7%).

Limitations

- ◆ Because the sources of information in most countries were key persons working in the field of epilepsy and possibly members of a professional organization, the data pertain mainly to countries where there are physicians or neurologists with an interest in epilepsy. It is therefore possible that the above figures are overestimated.
- ◆ Some of the epilepsy specialists working in the country might not be members of any organization. The number of members would therefore underestimate the total number of professionals working in the field of epilepsy care.
- ◆ Information is lacking regarding the coverage of the population by the activities specified within the countries.
- ◆ Information concerning the quality of services is not available.
- ◆ Many of the professional organizations reported that they are also involved in providing services and care for people with epilepsy; as it was not asked for, this activity has not been brought out by the results of the survey.

Conclusions

- ◆ The presence of professional organizations of epilepsy specialists is an important aspect of the provision of the highest quality of care and improved well-being for those afflicted with epilepsy and other related seizure disorders. Efforts should be made to encourage the development of such professional organizations.
- ◆ The professional organizations should be more involved in promoting the education, training and research activities in epilepsy.
- ◆ A large number of professional organizations of epilepsy specialists work under the umbrella of ILAE (which has Chapters in over 90 countries), leading to collaborative efforts in various activities related to patient care, education, training and research.



Introduction

- ◆ Lay associations refer to voluntary organizations, charitable groups or advocacy groups working in the area of epilepsy, and groups of patients and service carers.

Salient findings

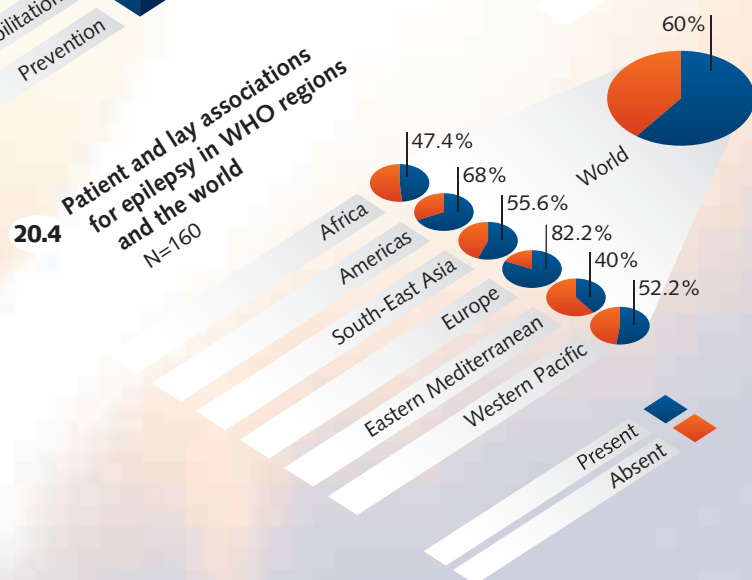
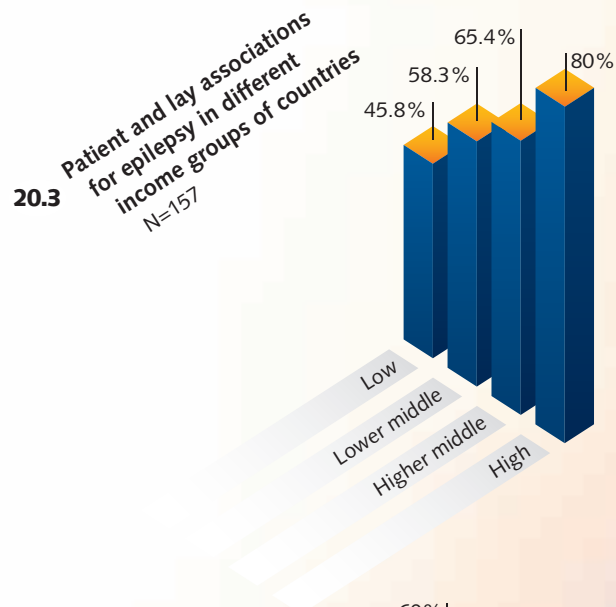
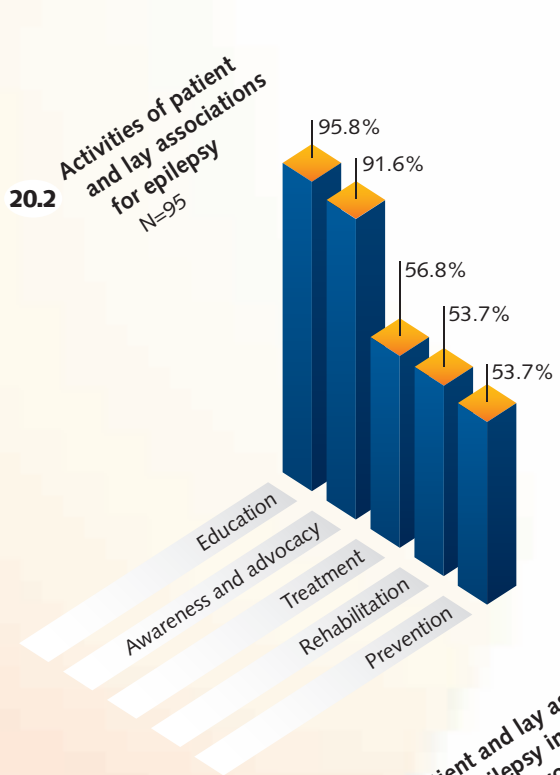
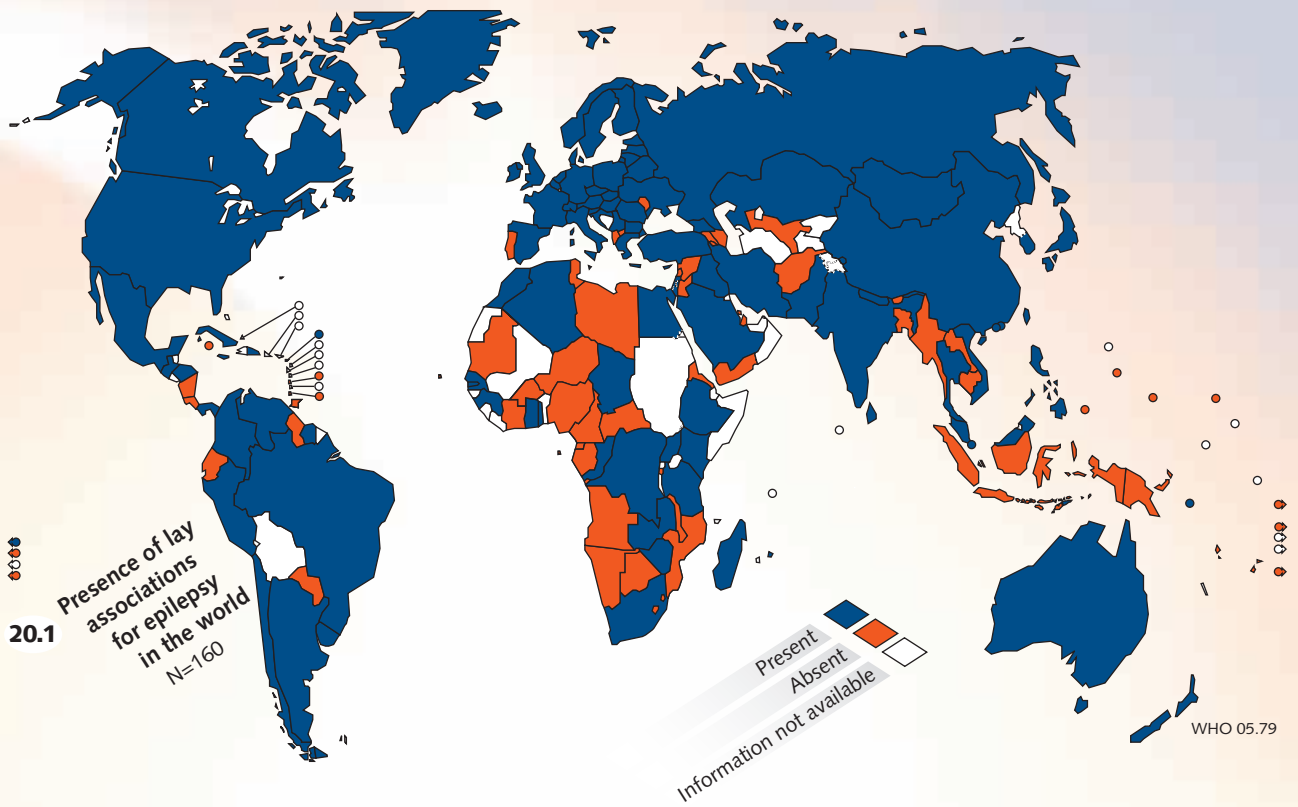
- ◆ Of the responding countries, 60% have at least one patient or lay association working in the field of epilepsy.
- ◆ No patient or lay epilepsy association exists in 60% of the responding countries in the Eastern Mediterranean, 52.6% in Africa, 47.8% in the Western Pacific, 44.4% in South-East Asia, 32% in the Americas, and 17.8% in Europe.
- ◆ Patient or lay epilepsy associations are absent in 54.2% of low-income countries, compared with 20% of high-income countries.
- ◆ The patient or lay epilepsy associations are involved in a range of activities in responding countries including: education (95.8%), awareness and advocacy (91.6%), treatment (56.8%), rehabilitation (53.7%) and prevention (53.7%).

Limitations

- ◆ Because the sources of information in most countries were key persons working in the field of epilepsy, the data pertain mainly to countries where there are persons with an interest in epilepsy. It is therefore possible that the above figures are overestimated.
- ◆ Many countries mentioned the presence of a patient or lay association, but information regarding coverage of the population is lacking. In most cases these organizations are working only in selected areas of a country.
- ◆ Some of the patient or lay associations mentioned by the respondents are wide ranging welfare organizations with a much broader scope than assistance to people with epilepsy.
- ◆ Information concerning the quality of services is not available.

Conclusions

- ◆ The lay associations are important in providing care for people with epilepsy. They have a significant role in dealing with non-medical aspects (education, employment, insurance, driving, etc.) which are crucial issues in providing epilepsy care.
- ◆ The patient associations may also complement the activities of professionals working in the field of epilepsy by providing the above-mentioned services.
- ◆ Many of the local patient associations are members of IBE.
- ◆ The role of patient and lay associations in improving the quality of life of people with epilepsy needs to be recognized and supported.
- ◆ There is an urgent need to establish more patient groups, especially in low-income countries, to improve consumer participation in health care and promote self-management.



Prof Giuliano Avanzini

Founded in Budapest, Hungary, on 29 August 1909, the International League Against Epilepsy (ILAE) includes at present over 90 national Chapters in all parts of the world. It collaborates with the International Bureau for Epilepsy (IBE) and the World Health Organization (WHO) with the aim of reaching the following objectives:

- ◆ advancing and disseminating knowledge of epilepsies throughout the world;
- ◆ encouraging epilepsy research;
- ◆ promoting the prevention, diagnosis and treatment of epilepsy, advocacy on epilepsy issues, and the care of everybody suffering from epileptic disorders;
- ◆ improving education and training in the field of epilepsy.

Throughout its nearly 100 years of existence, ILAE has continued its efforts to encourage the establishment and maintenance of new national Chapters, and to create and maintain the administrative and financial infrastructures necessary to allow it to reach its main goals. One important step has been the establishment of periodic worldwide or regional ILAE Chapter meetings (Chapter Conventions) to discuss and design ILAE policies on the basis of emerging needs and the recommendations of the Resource and Problem Oriented Commissions nominated by the ILAE President.

The ILAE Chapters are currently organized in six regions: Africa, Asia, the Eastern Mediterranean, Europe, Latin America and North America. Each of these has an ILAE Regional Commission whose officers are elected every four years by their respective Chapters.

In order to pursue its aims, ILAE works closely with IBE; since 1997, this collaboration has been reinforced and reoriented by the launch of the Global Campaign Against Epilepsy (GCAE) in partnership with both IBE and WHO. As many of the major achievements of the GCAE are reported elsewhere in the Atlas, I concentrate here on the specific contributions of ILAE.

In line with its constitutional objectives, the main strategic priority of ILAE is to improve epilepsy care throughout the world. The results of a number of assessments of the extent to which national and international health-care systems can meet the needs of patients with epilepsy demonstrate that there is a significant gap between the number of people with active epilepsy and the number whose seizures are being appropriately treated, particularly in developing countries. The various reasons for this include the insufficient education of caregivers about epilepsy, the lack of comprehensive epilepsy care programmes and facilities, financial problems leading to insufficient equipment and AED supplies, and the limited use of epilepsy surgery.

The treatment gap has been tackled by supportive actions aimed at facilitating the access of patients to specialized epilepsy services and increasing the level of existing health-care facilities. ILAE has also promoted and supported Chapter activities designed to encourage governments and health ministries to respond to the needs for greater epilepsy awareness, education, diagnosis, treatment, care, services and prevention.

Within the context of GCAE, a number of Demonstration Projects have been started with the aim of optimizing epilepsy care in Africa, Asia and Europe. Demonstration Projects assess the needs and resources of a given territory and offer training and technical information for local health-care providers that have an immediate impact on the quality of local epilepsy care. In more general terms, they create the basis for the development of a successful model of epilepsy care that can be integrated with national, regional and, finally, global health-care systems. Demonstration Projects have so far been developed in Argentina, Brazil, China, Pakistan, Senegal and Zimbabwe.

Education

ILAE has paid considerable attention to the establishment of local, national, regional and international education programmes aimed at improving the expertise of epilepsy care providers throughout the world. Every national Chapter promotes local epilepsy courses for neurologists, general practitioners, technicians and nurses, and organizes at least one annual course at national level. Moreover, regional programmes are being implemented on the basis of the pioneering experience of the European Epilepsy Academy (EUREPA), which was created by the ILAE European Commission and now acts as ILAE's educational agency. In addition to promoting and accrediting courses in various parts of Europe, and helping other ILAE Regional Commissions to organise similar initiatives, EUREPA has developed two innovative educational models: train-the-trainers courses and European Epileptology Certification.

The aim of the train-the-trainers courses is to turn experienced personnel into qualified teachers of epileptology. The activities carried out by the trainers prepared by the courses organized over the last five years have significantly contributed to raising the profile of epilepsy care across Europe, and this success has prompted other ILAE regions to launch similar courses whose initial impact on epilepsy care also appears to promise further positive results. European Epileptology Certification can be obtained by completing an 18-month educational programme based on periods of training in selected institutions that allow the accumulation of credits. This ongoing initiative will lead to the establishment of a list of accredited epileptologists to whom patients with epilepsy can refer.

The biennial International Epilepsy Congress and Regional Epilepsy Congresses, which take place in alternate years, are also educational events as they include specifically designed educational activities organized by EUREPA and the ILAE commissions. In addition, in 2002, an annual residential epilepsy summer school for young epileptologists from throughout the world was started at the International School of Neurological Sciences, Venice, Italy. Since its foundation, the School has trained students from 64 countries, including six which do not yet have an ILAE Chapter, belonging to all ILAE regions. The interaction between students and teachers and among the students themselves resulted in several ongoing international collaborative projects which are contributing to raising awareness of epilepsy care in several developing areas.

The feedback provided by national Chapters at the Chapter Conventions has demonstrated that these educational activities have made a significant impact on the improvement of epilepsy care, in large part because of the efforts made to ensure that programmes are tailored to the specific needs of different areas. An important contribution has been made by the ILAE Task Force for Subregional and Interregional Organizations, which facilitates spontaneous aggregations of countries with common cultural backgrounds even if they belong to geographically different regions.

Research

Any action aimed at making optimal epilepsy care available to patients throughout the world must take into account the advances made as a result of the synergy of basic and clinical multidisciplinary research; this requires a critical evaluation of the results that are continuously being made available to the scientific community. ILAE has created various commissions and task forces of authoritative specialists who assess how the new information can be translated in diagnostic and therapeutic terms, and produce ad hoc guidelines and recommendations. A crucial role in evaluating the clinical applicability of neurobiological results is played by the Neurobiology Commission. All of the commissions are

required to make sustainable recommendations that take into account the economic difficulties of the developing world and, furthermore, a Healthcare Policy Commission chaired by an economics expert has been appointed with the task of assisting ILAE to develop a worldwide affordable epilepsy care policy.

The main problems are the costs of diagnostic equipment and AEDs, and the difficulties in organizing epilepsy surgery programmes in countries with limited resources. Minimal requirements in terms of drug availability and diagnostic facilities have been recommended by Epidemiology, Therapeutic Strategies and Diagnostic Methods and Paediatrics Commissions, and the Commission of Neurosurgery has made recommendations for countries with limited resources.

In elaborating their health-care strategy, epileptology communities should not simply draw on the available scientific information but should also contribute to it by means of their own original investigations. I strongly believe that this is crucial if we are to meet specific local requirements and take into account specific socioeconomic situations. The ILAE Genetics, Neurobiology and Psychobiology Commissions have therefore been engaged in actions aimed at helping developing countries to establish research projects to face their individual problems. ILAE is active in promoting international collaborative research networks, facilitating partnerships between developed and developing countries, and sensitizing the relevant international institutions (the World Bank, WHO, UNESCO, the European Union, governments, etc.) to epilepsy research. Fellowships and grant programmes are being developed to allow young epileptologists to visit foreign laboratories.

This is only a short and by no means complete account of ILAE's role in fostering epilepsy care throughout the world. Much has already been done, but there is still more that needs to be done in order "to achieve a world in which no person's life is limited by epilepsy", to quote the masthead of ILAE's strategic plan, which is and will continue to be our inspirational mission.

Mr Philip Lee

The International Bureau for Epilepsy (IBE) collaborates closely with the International League Against Epilepsy (ILAE). Whereas ILAE is an association of physicians and other health professionals dealing with the medical aspects of the condition (see Section 21), IBE's focus is on the overall quality of life of people with epilepsy, especially as it relates to the social aspects of the condition.

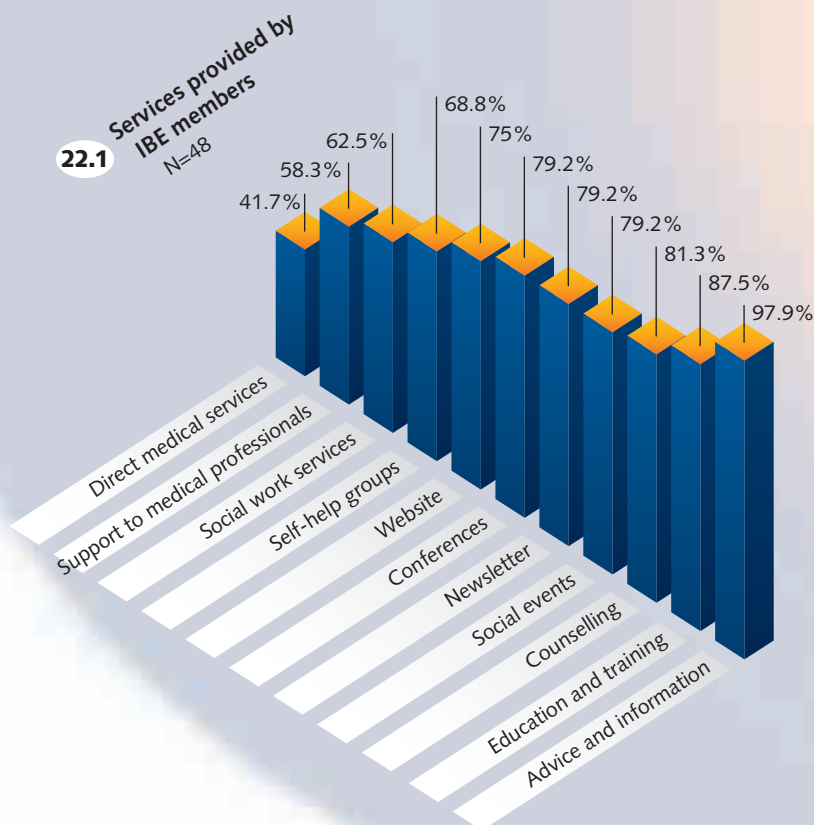
IBE comprises more than 100 member organizations around the world. Most of these are national epilepsy associations which between them represent millions of people with epilepsy and their families and carers. IBE provides a reference point for all its members, offering a global network of support, information and coordination. It also acts as an international advocate for epilepsy, promoting better care and treatment, increasing knowledge about the condition and working to achieve greater public acceptance of epilepsy to reduce the stigma that still attaches itself to the condition.

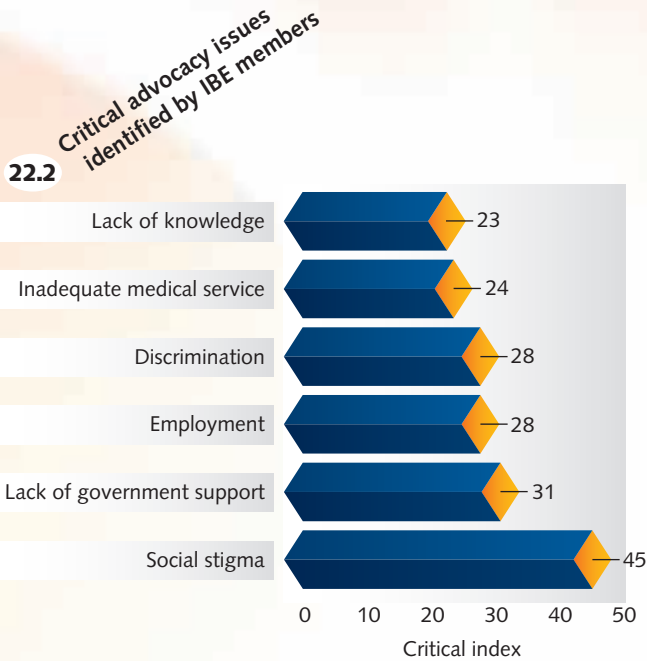
Patient-based nongovernmental organizations such as IBE's members play a dual role: firstly, as providers of direct medical and non-medical services; secondly, as influencers of policy, advocating on behalf of people with epilepsy as to their needs and wants from health-care providers.

Figure 22.1 shows the results of a survey of 48 IBE members in January–February 2005. It indicates their range of direct service activities and the percentage of members active in each area.

While the large amount of information, training and communication work based around patient and public awareness might be expected, it is worth noting that 41.67% of IBE member associations are engaged in providing direct medical services and 58.33% provide support to medical professionals. For example, in the United Kingdom, Epilepsy Action has funded more than 80 positions for specialist nurses in epilepsy within the National Health Service. In Chile, LICHE operates a drug bank to supply antiepileptic drugs to people with epilepsy; the success of this operation over the years has led LICHE to become one of the foremost suppliers in the country. Even more ambitiously, perhaps, IBE members in Mauritius and Romania have aspirations to establish their own national epilepsy centres.

In addition to direct services, 80% of IBE members surveyed reported that they are actively engaged in seeking to influence their governments and other decision-making and policy-making bodies in their countries. Figure 22.2 indicates the key advocacy and campaign issues as identified by IBE members. Clearly, the most important is combating the social stigma of epilepsy, followed by an apparent lack of government support for epilepsy in relation to providing financial resources and the political will to change things. Other social issues – poor employment opportunities for people with epilepsy and social discrimination – are ranked as being more critical than an inadequate medical service.





One of the challenges in developing countries is that epilepsy might not be perceived as such a threatening condition as HIV/AIDS, for example. In parts of sub-Saharan Africa this is rightly the case. Even in such circumstances, however, people with epilepsy cannot be ignored: they still need care and treatment for their condition. To ignore epilepsy because there are other more important health issues is not a reasonable or acceptable position to take.

The value of nongovernmental organizations with a specific interest in epilepsy is that they can help to identify the issues for politicians; to assess the scope of the problems, and to signpost practical, affordable and realistic strategies that can be applied and be integrated within a national health-care and social care policy. Such organizations therefore have a crucial part to play in collecting data to inform the political debate about health-care and social care priorities and in educating those in positions of power and influence to realize the things they can do to improve the lives of people with epilepsy.

IBE members provide a focus around which people with epilepsy can organize themselves, articulate their wants and needs and develop a sense of identity and common purpose. The proliferation of information technology (in particular the Internet) has enabled more people than ever before to be better informed about their condition. IBE members are playing a key role in the transfer of information and in facilitating people's understanding of the information they receive: this is knowledge management, and this is what empowers people. A patient-centred approach requires that patients be involved in their health care and be seen by others as equal partners and not merely the passive recipients of care and treatment. Patients are now more demanding of their health-care providers, be they medical professionals who deliver the care or politicians and policy-makers who decide what should be available and who should get it. Patients are increasingly seen as consumers of health care and, as consumers, they have an influence on both the providers and the policy-makers.

The emerging influence and role of patient-based nongovernmental organizations in direct health care is perhaps reflective of a wider change. Throughout the world, but acutely so in developing countries, there is a distinct and recognizable gap in terms of what resources are available and what resources are needed. Health care universally is marked by limited resources having to meet seemingly unlimited demand. As a result, the public sector is under increasing pressure. The private sector can and does fill some of the gap, but this level of provision brings its own problems and constraints, not least affordability and access for the poor who are most likely to be in need of care.

Epilepsy organizations are in a position to help, not just by articulating people's needs but also by identifying the resource gaps and helping to close them by contributing money, technical knowledge, professional expertise, training, equipment and people. By incorporating nongovernmental organizations and their resources into national plans to deal with epilepsy, governments can reduce the gap and bring about the possibility of real improvement.