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## International League Against Epilepsy – commissions, task forces and the Global Campaign Against Epilepsy

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### ILAE commissions and task forces (*Peter Wolf*)

Commissions and task forces have for many years been one of the most important resources of the ILAE. Indeed, one of the first tasks to be accomplished by an incoming president is to appoint the new commissions in consultation with the Executive Committee. Up to now no written rules have governed this process, but the present executive is attempting to change that and to make sure there is both continuity and innovation in the commissions' work. Ideally, there should always be some members of an outgoing commission who continue and others whose commitment ends to make place for new blood. One new stipulation will be that the outgoing commission chairs continue in the capacity of past-chairs.

This change will underscore a long-standing tradition that the incoming president consults with the outgoing commission chairs about the new commissions' composition and agenda. The latter could of course also be derived from the commission reports, but these have not always been delivered as expected. This was understandable when annual reports were required, and frequently there may not even have been much to report about, because a commission's work is often not spread out equally over 4 years. We will now expect a mid-term report after 2 years as well as an end-of-term report, which appears more useful.

Beyond these regular business reports, commissions often produce topic-centred reports, recommendations, guidelines and so on, which are very important contributions to the League's life. However, the process for publishing them also required some structuring. Now, once such reports and recommendations are accepted by the ILAE

executive, they will be published in *Epilepsia*, in principle following peer review. This last point is potentially contentious, because commissions are supposed to be boards that include the best expertise in the respective field. Would the reviewers then be super-experts chosen by the editors-in-chief? It is the task of the editors to deal with the question in a way that avoids conflict. They have until now been successful, as the peer-review process has been designed not to control the content of reports but to optimise their expression. This policy is acceptable to everybody.

Another issue for which a rule was needed was the authorship of commission reports. In the past, attribution took many different formats. The reports are commissioned and to some extent funded by the ILAE, and their publication in *Epilepsia* makes them official documents of the League. This has not always been visible enough or even visible at all. On the other hand, publishing the reports anonymously, just as commission documents, is unfair towards the commission members who provide their expertise and ideas on a voluntary basis and often devote considerable effort to compiling the reports. They should have the right to claim the publications. We now stipulate that commission work should be published with the commission members (and other contributors if applicable) as authors but with a subtitle that declares the paper to be a commission report.

Over the years, the number of commissions has increased as new topics came into focus that were complex enough to require the special attention of a group of experts. It is rare, however, that a commission declares its mission accomplished; rather, commissions tend to perpetuate their work. This is natural inasmuch as members'

involvement with their topics continues beyond the limited tasks which are given to an ILAE commission. But in the past it has happened that some commissions took on a life of their own, and the role of the ILAE president and executive were perceived as an intrusion rather than the basis of the commission's existence. The question whether commissions serve the ILAE or vice versa has not always been entirely clear. This difference of opinion is hardly malignant, however, and is more an expression of the healthy (and often productive) tensions that are common in an active society with many committed members.

Although for a long time expert input was organised in commissions, in recent years the task force format has increasingly come into use. It is in the nature of commissions to freely discuss the developments in their particular field (e.g. neurosurgery, genetics or epidemiology) and to advise the ILAE about them, developing guidelines and position papers mostly at their own discretion and as seems fit. Commissions view their commitment as ongoing, and the development of long-term strategies for their field as part of their task. In principle they continue to exist as long as there are substantial developments in their field that are relevant to epileptology and specific enough to require special expertise to be understood. The new commissions on education and on epilepsy care are prototypical of this approach. In contradistinction, a task force is given a specific problem to solve, after which it is dissolved. The topics to be addressed are typically defined by either the ILAE executive or another commission as part of its agenda (or several commissions working together).

In 1993, the ILAE instituted an entirely new type of commission: the regional commission. The first of these, the Commission on European Affairs, was formed as a way of dealing with separatist tendencies that had developed in the European region. What were the reasons for these? Why did highly respected people, deeply committed to the international epileptological agenda, consider separating from the ILAE? What was missing in the League's approach? Could the perceived problems have been solved within the existing structures if these had been improved? Nearly as soon as the European commission was established, it became clear that the League's general global agenda lacked the necessary flexibility and plasticity to accommodate the rapid growth of the organisation in the various regions, with their diverse problems and interests. But it also turned out that a regional commission structure together with a kind of regional parliament (the 'European

Advisory Council') provided an adequate response to the problem. It gave Europe and then other regions the possibility to develop their own identity and their own solutions to specific issues. After 1989, Eastern Europe had to be brought abreast of modern developments and integrated into global epileptology. The Western European chapters were quite willing to take the responsibility for achieving this, and the commission gave them the necessary basis. Education could be developed very efficiently with a regional academy as a platform that could also help to organise transnational European research when interesting new possibilities for European funding of research appeared. The region also developed a series of regional congresses with an expressed competitive outlook.

The Asian and Oceanian region faced a different set of issues. Major differences existed in the level of epileptological knowledge and care between the most, less and least developed countries in the region. Again, committed persons in the region took leadership and responsibility in a regional commission and developed a series of informational and educational meetings conducted in countries where the need was largest; a fellowship programme to educate key personnel; and certified EEG education. This agenda was very successful and went far to organise epilepsy in the region, with many new national chapters coming into existence. Another series of regional congresses was developed which steadily increased in attractiveness and quality.

In a similar development in Latin America, a region with a mixture of long-standing and very young national chapters, the decisive steps forward were to set up regional summer schools which brought together young talent from all over the region, to promote collaborative programmes with North America to develop specific fields such as epilepsy surgery and neurocysticercosis, and to establish subregions such as the Caribbean.

The ILAE executive would not have developed these approaches by itself; they were the consequence of giving local experts the freedom to develop their own agenda. A necessary precondition for this was that the regions had significant input into the composition of their commissions. Unlike problem-oriented commissions, these are not appointed top-down. Instead, the chapters of the region elect the major part of their membership, supplemented by two members appointed by the ILAE president who also designates the chair and secretary of the regional commissions. The flexibility of this approach has proved very successful, and the growth of commission

work on the whole testifies to a vibrant League in constant development.

Every 2 years, the commission chairs meet for a stand-alone long-range planning meeting. The last of these took place in Brussels in the autumn of 2007. The participants were overwhelmed to realise the incredible richness of the League's manifold activities across the field of epilepsy. Particular attention was given to the new commissions of the 2005–2008 administration, i.e. the Commission on Education and the Commission on Epilepsy Care. An educational commission had existed earlier but had not yet developed an ongoing agenda. Now, education has become top priority of the League, and the educational commission is one of the most active of the commissions, with a large agenda.

The Commission on Epilepsy Care was established as a successor of the previous Commission on Healthcare Policy, with a broader remit. It involves representatives of all regions and should provide a closer link between the ILAE and one of the most important recent international initiatives in the field of epilepsy: the Global Campaign Against Epilepsy of the ILAE, the International Bureau for Epilepsy (IBE) and the World Health Organization (WHO).

### THE ILAE/IBE/WHO Global Campaign Against Epilepsy: 'Out of the Shadows' (Edward Reynolds)

The ILAE/IBE/WHO Global Campaign Against Epilepsy was launched in the summer of 1997 and is now in its 11th year. Its ambitious aim has been to bring together three global organisations, the ILAE, representing professionals; the IBE, on behalf of patients and public; and the politically influential WHO, in a joint partnership and initiative to address the hidden, neglected but global problems of people with epilepsy. This objective is reflected in the Campaign title and logo, 'Out of the Shadows'.

#### Global problem of epilepsy

Epilepsy is the world's most common serious brain disorder and a unique global problem that affects all ages, races, social classes and countries. Epidemiological studies have shown that it is uniformly distributed around the world with only slight variations in prevalence influenced by local environmental factors such as trauma associated with wars, road traffic accidents or poor obstetric care;

**Table 1** Treatment gap studies in developing countries 1988–1996. (From Reynolds 2001 with permission)

Country	Percentage
Ecuador	88
Ethiopia	98
Guatemala	69
India	75
Pakistan	94
Rural	98
Urban	73
Philippines	85
Sudan	60

or brain infections associated with poverty, malnutrition and epidemics; or age-related diseases in more developed countries. Historically it can be traced to all ancient civilisations. For example, Babylonian descriptions of epileptic seizures in the second millennium BC are very similar to those we see today (Kinnier Wilson and Reynolds 1990). Epilepsy imposes enormous physical, psychological, social and economic burdens on individuals, families, communities and countries, compounded by the misunderstanding, fear and stigma that has prevailed for millennia and is still widespread today. These problems are universal but are greatest in the developing world where 85% or at least 50 million people with active epilepsy live and where, at the start of the Campaign, as many as 60–98% received no adequate treatment, the so-called treatment gap (Table 1) (Kale 1997, Reynolds 1997).

#### Global partners

Following the birth of the ILAE in Europe in 1909 and its struggle to survive between the two world wars, the organisation grew steadily in the second half of the 20th century. Between 1993 and 1997 the number of national ILAE chapters grew from 40 to 62, with chapters in every continent, making it a truly global organisation. Likewise the IBE, which was founded in 1962, expanded steadily such that by 1997 its 60 chapters also reflected a similar international dimension. By the mid-1990s both the League and the Bureau were developing regional commissions and structures. Furthermore, both the League and the Bureau were non-governmental organisations (NGOs) that were formally affiliated with WHO, the United Nations organisation, headquartered in Geneva, that is responsible for global political action in the field of public health. Finally, during the early 1990s the League

and the Bureau had established very good working relations, with separate but interlocking executive committees, which enabled them to collaborate on projects of common interest, such as international congresses or the Global Campaign, while pursuing other matters of related but separate interest independently.

### Birth of the concept

As presidents of ILAE and IBE, I (Edward Reynolds) and Hanneke de Boer attended our first two annual meetings of the neuroscience NGOs associated with WHO, which were held in Geneva in December 1993 and 1994. It seemed that these were merely forums for the exchange of information, but it occurred to me that the potential existed for a much more active and effective relationship with WHO. I therefore sought a personal meeting with Jorge Costa e Silva, then head of the Department of Mental Health of WHO. It took a year to arrange the meeting, which was postponed three times. When it eventually took place in Geneva on 16 January 1996, I was pleasantly surprised. I brought with me Pierre Jallon, whom I had appointed chairman of the ILAE Commission on Developing Countries, not only because of his experience with and commitment to developing countries but also because he was based at the University of Geneva in close



Edward Reynolds, ILAE president 1993–1997.

proximity to WHO. Professor Costa e Silva brought with him, as expected, Leonid Prilipko, head of the Section of Neuroscience, and also, unexpectedly, Professor Li Shi Chuo, who not only had a personal interest and commitment to people with epilepsy in China but also was the current chairman of the executive board of WHO. There was a considerable meeting of minds that day in which the concept of the ILAE/IBE/WHO Global Campaign Against Epilepsy was born.

WHO rapidly agreed to the Campaign, no doubt because of the political influence of Li Shi Chuo and Jorge Costa e Silva and the encouragement of Leonid Prilipko. Promoting the idea to the League and the Bureau initially proved more difficult, partly because for some board members the concept of a novel partnership with WHO seemed too ambitious and bureaucratic and partly because some feared that the Campaign would divert limited resources and funds away from other important goals of each organisation. However, in June 1996 the ILAE's Commission on Developing Countries arranged a 2-day workshop in Geneva with experts from the ILAE, the IBE and the WHO, and representatives from every continent. Epidemiological, medical, social and economic aspects of epilepsy in developing countries were reviewed as a platform on which to build the Campaign (Jallon 1997). Encouraged by myself and Hanneke de Boer, the League and Bureau then agreed that the potential benefits for people with epilepsy everywhere outweighed the potential challenges and risks of the Campaign, which was therefore formally announced at the ILAE European Congress in The Hague, Netherlands, and at the ILAE and IBE Asian and Oceanic Congresses in Seoul, South Korea, in September 1996.

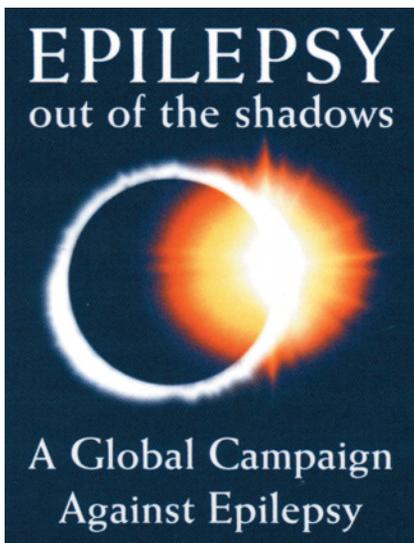
### Mission, strategy and objectives

It was agreed that the mission statement of the Campaign would be 'To improve acceptability, treatment, services and prevention of epilepsy worldwide'.

The strategy of the Campaign included two parallel and simultaneous tracks: (i) raising public and political awareness and understanding of epilepsy, and (ii) encouraging and supporting departments of health in identifying needs and promoting education, training, treatment, services, research and prevention nationally.

The more specific objectives of the Campaign are as follow:

1 To increase public and professional awareness of epilepsy as a universal, treatable brain disorder



The Epilepsy 'Out of the Shadows' logo was chosen for its universal appeal.

- 2 To promote public and professional education about epilepsy
- 3 To change attitudes, dispel myths and raise epilepsy on to a new plane of acceptability in the public domain
- 4 To identify the needs of people with epilepsy on a national, regional and global basis
- 5 To encourage governments and departments of health to develop their own national campaigns to improve prevention, diagnosis, treatment, care, services and public attitudes

A key concept of the Campaign is that it includes interrelated global, regional and national components (Reynolds 2001). WHO has six regional offices which are closely integrated with the Geneva headquarters. In recent years the League and the Bureau have developed their own regional structures and activities which can interact with WHO at the regional level. Ultimately, the global and regional activities of the Campaign are designed to stimulate, encourage and assist national governments and epilepsy organisations to develop their own 'Out of the Shadows' campaigns, based on their own local knowledge of the problems and solutions for people with epilepsy. As the highest decision-making body of WHO, the General Assembly, is made up of a national representative, often the minister of health, from each country, then the more

countries that get involved in the Campaign, the greater the impact at the global level.

### Launch of the Campaign

The first phase of the ILAE/IBE/WHO Campaign to bring epilepsy out of the shadows was formally launched in the presence of the leadership of WHO, the League and the Bureau in Geneva on 19 June 1997 and again 2 weeks later on 3 July 1997 in Dublin at the 22nd ILAE/IBE International Congress in the presence of the Irish president, Mary Robinson, later UN Commissioner for Human Rights. In Dublin the Campaign held a symposium on the politics of epilepsy at which John Bowis, former UK Minister of Health; Tony Coelho, former US congressman, with epilepsy; Mary Benotti, Irish MEP; and Senator Joe Doyle, Irish senator and then Lord Mayor of Dublin, who also had epilepsy, all participated. Earlier in the mid-1990s I had the privilege of the support of John Bowis, in his capacity as minister of health, for a UK-based initiative for epilepsy (Reynolds 1995). It was this impressive experience of local and national political support that encouraged me to approach WHO with the idea of a more ambitious international political initiative. John Bowis became a valuable model, guide and supporter of the Campaign, not least through his later role as an MEP in the European Parliament, where he continued to promote the Campaign.

### Phase 1: 1997–2001

As emphasised by Gro Harlem Brundtland, the director-general of WHO, in her speech at the launch of the second phase of the Campaign on 12 February 2001, the first phase of the Campaign focused on the first three objectives: increasing awareness, creating acceptance and improving education. The successful outcome of this phase is reflected in the milestones summarised in Table 2 and the higher priority given to the Campaign by WHO, which culminated in the second phase plans and launch (Reynolds 2000, 2002).

At the global level, the most important achievement was the development and acceptance in December 1999 of a 'Cabinet Paper' on the Global Campaign which raised the status of the Campaign to the highest level within the new priorities of the newly reorganised WHO under Doctor Brundtland. Epilepsy was the first neurological disorder to be accorded this status. The ILAE/IBE/WHO Global Campaign has become the model for other neuroscience

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**Table 2** ‘Out of the Shadows’ Campaign programmes (phase 1).  
(From Reynolds 2001 with permission.)

<i>Scale</i>	<i>Projects</i>
Global	Awareness raising and education: Cabinet paper, December 1999, leading to launch of phase 2, February 2001
Regional	Regional conferences and declarations: Europe, October 1998 Africa, May 2000 Latin America, September 2000 Asia and Oceania, November 2000 North America, December 2000 European White Paper Preparation
National	Local initiatives in over 50 countries: Preparation for demonstration projects in selected developing countries

NGOs that aspire to global campaigns for their own neurological disorder, for example, more recently, headache. Indeed, the Campaign Against Epilepsy was at the forefront of WHO’s 2001 World Health Day and its World Health Report on mental and brain disorders.

At the regional level, a major activity was a series of regional conferences and declarations designed to raise awareness, acceptance and education about epilepsy and the Campaign (Reynolds 2001). The first of these was the European Declaration on Epilepsy in October 1998, following a conference of more than 100 professionals, patients and public, and politicians from all over Europe in Heidelberg, sponsored by the German Government. In the year 2000 similar regional declarations, based on the European format, were developed in Africa in Senegal, Latin America in Chile, Asia and Oceania in India, and North America in the United States. In all, more than 1,200 expert representatives from more than 100 countries have participated in these regional conferences and declarations.

One of the main objectives of these global and regional activities has been to encourage national chapters and departments of health to develop their own national or local ‘Out of the Shadows’ initiatives. A subsidiary objective has been to stimulate the establishment of new chapters of the ILAE and IBE in countries where they do not exist. By 2001, 50 countries had begun local projects under the auspices of the Campaign.

### Phase 2: Launch

Following the success of phase 1 and the elevation of the Campaign to one of WHO’s highest priorities, a high-profile launch of the second phase of the Campaign was held in Geneva on 12 February 2001, led by the director-general of WHO, Gro Harlem Brundtland (Reynolds 2002). Also participating were the executive leadership of the League, the Bureau and the division of non-communicable diseases and mental health of WHO, together with representatives of 13 missions of WHO country members, 24 national chapters of the ILAE and IBE, 4 NGOs in neuroscience and neurology, and 17 private sector organisations.

Doctor Brundtland’s address at this launch (see Reynolds 2001, and figure on p. 111) is probably the most important political public health statement about epilepsy in the history of the disorder. Emphasising the scale of the problem, especially in developing countries, she indicated that epilepsy was at the forefront of her plans for the 2001 World Health Day and World Health Report on mental and brain disorders. The collaboration of the ILAE, IBE and WHO had illustrated what could be achieved when people with different backgrounds and roles came together with a shared purpose. By concentrating on the first three objectives of the Campaign in phase 1 – increasing awareness, creating acceptance and improving education – the foundations for achieving the last two objectives – identifying and addressing needs at national government level – had been laid. A central feature of phase 2 would be demonstration projects to assess the number of people with epilepsy in the project area and to train primary healthcare workers within existing primary health services how best to diagnose and treat epilepsy patients, beginning in China, Senegal, Zimbabwe and Argentina, later changed to Brazil.

At the launch, Hanneke de Boer expanded on the plans for phase 2 and I summarised the history of the birth of the Campaign and of phase 1. Jerome Engel, Jr., president of the ILAE presented a global medical view of epilepsy; Philip Lee, president of the IBE, a social view; John Bowis, MEP, a political view; and Carol d’Souza, from India, a patient’s view. The launch was followed by a half-day symposium on the challenges facing the Campaign, including the global burden of epilepsy (Matilde Leonardi), the psychosocial burden of epilepsy (Gus Baker), the treatment gap (Rajendra Kale), demonstration projects (Josemir Sander), regional declarations and ‘white papers’ (Peter Wolf), and finally the problem of epilepsy in children and adolescents (Natalio Fejerman) (Reynolds 2002).

### Phase 2: Demonstration projects

The aims of demonstration projects are as follows:

- 1 To estimate the prevalence of untreated active epilepsy
- 2 To assess the efficacy and validity of a training programme for health professionals
- 3 To promote a change of attitude in the community, i.e. dispel stigma
- 4 To eradicate preventable causes of epilepsy
- 5 To reduce the treatment gap and the psychosocial burden
- 6 To develop models of epilepsy treatment and care for integration in health services

Each demonstration project includes educational and social intervention, epidemiological assessment and case finding, treatment and service delivery, and outcome measurement. A central objective is the causes and reduction of the treatment gap (Meinardi *et al.* 2001). If a demonstration project is successful, it should illustrate good practice in providing services for people with epilepsy in a resource-poor country, which will serve as a model to be extended to the rest of the country and, if appropriate, to neighbouring countries. Criteria for selecting resource-poor countries include the availability of political and personal contacts, willingness to participate, availability of a WHO centre or country representative, an IBE and an ILAE chapter, a regular and basic supply of an antiepileptic drug and the facility of communication.

### Interim reports

#### *Western Pacific Region: China*

The most successful and advanced demonstration project is in China. In an initial survey of 55,000 people in six provinces of China, the lifetime prevalence of epilepsy was 7 per 1,000, higher than previously suspected, and implying about 9 million people with epilepsy. Eighty-seven percent of those studied included convulsive seizures, either primary or secondary, but EEGs were not undertaken. The rest included partial or unclassifiable seizures without convulsions. The prevalence of active epilepsy, that is at least two seizures in the last year, was 4.6 per 1,000. Of those with active epilepsy, 41% had never received appropriate treatment (treatment gap), 35% had irregular treatment and only 25% had been given reasonable regular doses of antiepileptic drugs. Of those with active epilepsy, 63% had not received antiepileptic treatment in the week before the survey (Wang *et al.* 2003).

This epidemiological study was then extended and followed by a large community-based intervention trial of phenobarbital in eight rural counties of six provinces, which covered a population of over 3 million people. As a result of the survey and a vigorous community awareness programme, 2,455 patients with convulsive seizures were recruited to the trial, managed by specially trained primary healthcare workers under the supervision of neurologists, who confirmed the diagnosis. The age of the patients ranged from 2 to over 60 years, but 63% were between 15 and 44 years, and 11% between 2 and 14 years. The mean duration of epilepsy was 15.5 years, and the median convulsive seizure frequency was 10 per year. Eighty percent of patients had previously experienced intermittent traditional Chinese medicine, acupuncture, folk medicines or antiepileptic drugs. In patients who completed 12 months of treatment, 68% experienced a reduction in seizure frequency of over 50%, and one-third were seizure-free; in patients completing 24 months' treatment, 72% had at least a 50% reduction and one-quarter were seizure-free. The probability of retention of medication was 0.84 at 1 year and 0.76 at 2 years. Adverse events were said to be mild and infrequent but, of 597 patients who withdrew from the study, at least 5% were due to unacceptable side effects of medication (Wang *et al.* 2006).

The authors concluded that this simple protocol involving the identification and treatment of patients with convulsive epilepsy with phenobarbital by specially trained primary healthcare workers under the supervision of neurologists in rural communities with limited resources was successful, such that this approach has been extended to 10 further locations in China and will become a national programme.

#### *Pan-American Region: Brazil*

The prevalence of epilepsy in relation to socioeconomic status has been surveyed in three areas of two towns in south-east Brazil: Campinas and São José do Rio Preto. Out of a total population of 96,300, 54,100 were screened. The lifetime prevalence of epilepsy was 9.2 per 1,000 with a mean age of 38 years. There were no differences or trends over four categories of socioeconomic status. However, the prevalence of active epilepsy in the previous 24 months, which overall was 5.4 per 1,000, was much higher in more deprived (7.5 per 1,000) than in less deprived patients (1.6 per 1,000). Overall, 38% were on inadequate treatment and 19% were on no treatment

at all. There were no differences in the treatment gap across the socioeconomic groups, which therefore did not explain the higher prevalence of active epilepsy in poorer groups. These findings are thought to represent a best-case scenario in Brazil, as the two towns are in one of the wealthier regions of the country with good public health and private care facilities and free medication (Noronha *et al.* 2007). On the other hand, 53% of patients with active epilepsy in Honduras were not receiving medical treatment (Medina *et al.* 2005).

#### *African Region: Senegal*

The Pikine Health District is a poor suburb of Dakar with a population of 480,000. Waterworks serve only 40% of the houses, and there are poor sewerage systems that contribute to a high risk of bacterial and parasitic infections. Some limited primary maternal and infant health plans exist. In a random survey of 4,500, the prevalence of active epilepsy in the previous 12 months was 14.2 per 1,000, much higher than in the above Chinese and Brazilian studies. Thirty-nine percent were below the age of 20 years, and 23.4% had never had antiepileptic medication. The adequacy of treatment among the remainder was not assessed. In a survey of knowledge, attitude and practice in the same population, of which 36% were uneducated and 8% unemployed, epilepsy was thought to be caused by evil spirits in 51% and contagious in 35%. Forty percent would not let their child play with a child with epilepsy, and two-thirds were not in favour of marriage with a person with epilepsy (Ndoye *et al.* 2005).

#### *African Region: Zimbabwe*

The Hwedza district population of 90,350 is entirely rural and has only two physicians but a well-developed primary healthcare system, including primary care nurses and health technicians. In a random sample of 6,274, 84 had epilepsy, giving a prevalence of 13.4 per 1,000, similar to other African countries, including Senegal. The treatment gap was estimated to be 93%. A limited education intervention project reduced the treatment gap to 83%. This demonstration project has been limited and delayed by the ongoing deteriorating political and economic environment in Zimbabwe.

#### *Other countries*

Since the original four demonstration projects envisaged at the launch of phase 2, several other countries have

initiated projects based largely on the Campaign model. They include the Congo in the African Region, and India, Indonesia, South Korea, Maldives, Myanmar and East Timor in the South-East Asian Region. The most recent addition has been a project in Georgia.

#### **National initiatives**

As of 2008, 103 countries or chapters have initiated projects under the umbrella of or stimulated by the Campaign, which are beyond the scope of this chapter.

#### **Other global projects**

##### *Epilepsy atlas*

In order to assist departments of health, professional and lay NGOs and anyone else involved in the provision of epilepsy care, the Global Campaign secretariat undertook a major review of epilepsy services available throughout the world. The survey began in 2002, employing a questionnaire with the assistance of WHO regional and country offices, and ILAE and IBE chapters. Data were collected from 160 countries, and the information was categorised and published according to WHO regions and country income (*Atlas* 2005). The survey included primary care, diagnostic, inpatient and specialist services, including neurosurgery; the treatment gap and availability of antiepileptic drugs; the availability of healthcare professionals of all kinds and of training and education opportunities; and the role of professional and lay organisations. Overall, the results confirm the serious lack of resources for epilepsy care in the world in contrast to the scale of the need. As expected, there are considerable inequalities across regions and especially across income groups, although when it comes to epilepsy care most countries are developing countries.

In preparing the global atlas, a number of WHO regions prepared reports on the implementation and future planning of the Campaign in the region.

##### *Epilepsy and stigma*

Within the framework of the Campaign and supported by a grant from the National Institutes of Health in the United States, a Collaborative Research Project on Epilepsy Stigma (CREST) is under way in China and Vietnam. The project involves ethnographic studies to explore prevailing beliefs and attitudes toward epilepsy within these two countries and to relate them to models of stigma

and culturally specific interventions. Based on a literature review, six levels of intervention in antistigmatisation campaigns are recognised: the cognitive level, needing educational intervention; the affective level, needing psychological intervention; the discrimination level, needing legislative intervention; the denial level, needing linguistic intervention; the economic level, needing political intervention; and the evolutionary origin, requiring intellectual and cultural intervention.

#### *Epilepsy and legislation*

Stigmatisation leads to discrimination. People with epilepsy are among the most vulnerable in society and experience prejudicial and discriminatory behaviour in many spheres of life across all cultures. Within the context of the Campaign an international working group of professionals, patients and lawyers is reviewing legislation that addresses discrimination and protects the human rights of people with epilepsy. This is being undertaken by a questionnaire piloted in at least two countries of different incomes within each of the six WHO regions. It is hoped to identify discrimination and human rights issues that need to be addressed; to develop a framework for reforming laws and regulations related to epilepsy; and to develop information and instruments for advocacy and lobbying.

#### Conclusions

This interim summary of the Campaign can only give an overview of the enormous amount of collaborative activity that has evolved at the global, regional and national levels over the last decade within the League, the Bureau and WHO, and at the growing local level where the objectives are ultimately targeted for the benefit of people with epilepsy all over the world. More details of the Campaign can be obtained from the annual reports that have been published each year since 1999. So many colleagues in all three organisations, in other organisations and in all walks of life, including patients and their relatives, have given their time and effort to this Campaign that it is impossible to acknowledge them all here. I would, however, like to thank Hanneke De Boer of the IBE and Leonid Prilipko of WHO, who sadly died in 2007, with whom it was a pleasure to work from the beginning of the Campaign.

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