Global Campaign Against Epilepsy

out of the shadows

World Health
Organization

International
Bureau for Epilepsy

International League
Against Epilepsy

The Campaign at a glance

A Global Campaign Against Epilepsy is much needed – the burden of epilepsy is underestimated and the means available to reduce it are underutilized. The problem is too complex to be solved by individual organizations.The three leading international organizations working in epilepsy have therefore joined forces to bring epilepsy "out of the shadows". The Campaign will assist governments worldwide to make sure that diagnosis, treatment, prevention and social acceptability of epilepsy are improved.

The Campaign strategy

Working along two parallel tracks, the Campaign will:

- raise general awareness and understanding of epilepsy;
- support Departments of Health in identifying needs and promoting education, training, treatment, services, research and prevention in their countries.

The Campaign tactics

- To generate Regional Declarations on Epilepsy, produce information on epilepsy for policy-makers, incorporate epilepsy care into National Health Plans, and facilitate the establishment of national organizations of professionals and lay persons who are dedicated to promoting the well-being of people with epilepsy.
- To help organize Demonstration Projects that illustrate good practice in the provision of epilepsy care.

The Global Campaign is managed by a Secretariat consisting of representatives of the three responsible organizations:

World Health Organization (WHO)
International League Against Epilepsy (ILAE) professionals
International Bureau for Epilepsy, (IBE) lay persons

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Why have a Global Campaign Against Epilepsy?

A Global Campaign Against Epilepsy is necessary because the burden of epilepsy on individuals and communities is far greater than previously realized. The problem is too complex to be solved by individual organizations. The three leading international organizations working in epilepsy have therefore joined forces to bring epilepsy "out of the shadows".

The Campaign is conducted by the World Health Organization (WHO) in partnership with the International League Against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE). The aims of the Campaign are to provide better information about epilepsy and its consequences and to assist governments and those concerned with epilepsy to reduce the burden of the disorder.

Facts about epilepsy

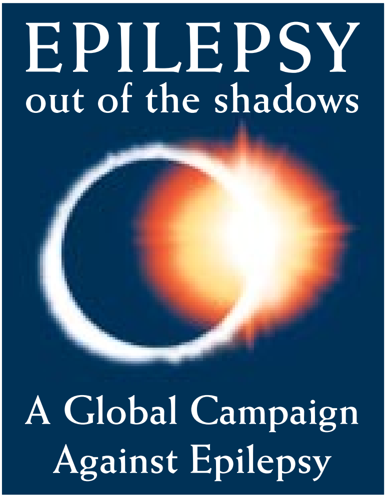
Epilepsy is a chronic noncommunicable disorder of the brain. It occurs all over the world. In all areas, no less than three out of every thousand people – and in several places over 40 per thousand (4%) – are affected[2]. Every year, among every 100 000 persons there will be 40 – 70 new cases [3].

The symptoms of epilepsy are the seizures that occur at unpredictable moments. These may vary from frequent brief lapses of consciousness to short periods of automatic subconscious behaviour or convulsions of the whole body that make the person fall over and lose consciousness completely. Intervals between seizures or clusters of seizures may vary from less than an hour to one or two years. Even in the latter case, the consequences of having the disorder affect a person's every-day life.

From the first written record in 4000 BC until the present day, myths and superstitions have been associated with epilepsy. This is one of the reasons that, in many parts of the world, living conditions for people with epilepsy are far worse than might be expected, given the state of knowledge about epilepsy and the means available to stop seizures and restore complete participation in society. In addition, as long as a person is likely to have seizures, the family and close friends also suffer the burden of this disorder.

There is sufficient evidence available to show that 70 – 80% of people with epilepsy could lead normal lives if properly treated[4]. Unfortunately, there is also evidence that in many countries more than 50% of people with epilepsy (and in certain areas up to 90%) are not properly treated[1]. Part of this treatment gap* is attributable to insufficient recognition that the symptoms of which these people complain are caused by epilepsy.

(More information about epilepsy is given in Appendix 1)



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*The difference between the number of people with active epilepsy and the number whose seizures are being appropriately treated in a given population at a given point in time, expressed as a percentage

What is the Global Campaign?

Campaign strategy and tactics

The mission statement of the Campaign is: *"To improve acceptability, treatment, services and prevention of epilepsy worldwide"*.

Major goals are to ensure that epilepsy care is incorporated into National Health Plans and to facilitate the existence in every country of organizations of professionals and lay people who are dedicated to promoting the well-being of people with epilepsy.

In order to increase awareness of the problems caused by epilepsy and the means available to deal with them, conferences have been organized between key persons in health care administration and government and experts in the field of epilepsy. These conferences were held in the six WHO regions (Africa, the Americas, the Eastern Mediterranean, Europe, South-East Asia, and the Western Pacific) and have resulted in Regional Declarations on Epilepsy[5], White Papers[6] and regional reports.

In order to assist Departments of Health which are looking for tools applicable in their country to realize the objectives of the Campaign, Demonstration Projects are organized in a number of countries in different regions. These Demonstration Projects offer models of how to identify needs; how to educate and train staff involved in diagnosis, treatment, services, prevention and research; and how to promote education of the general public.

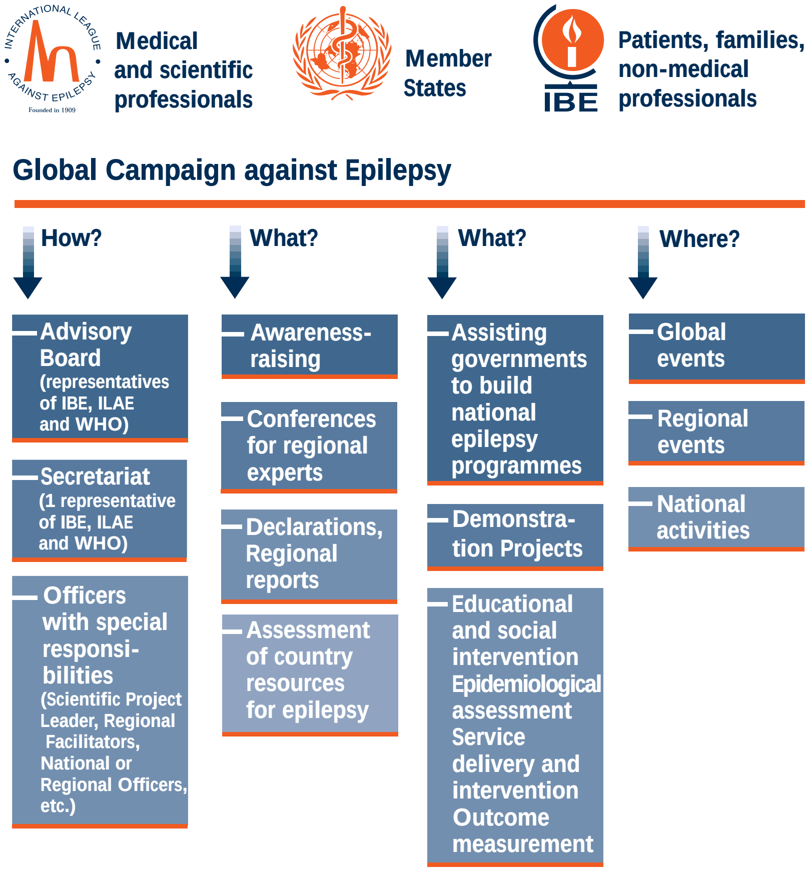
Management of the Campaign

Three organizations collaborate in the Global Campaign Against Epilepsy: WHO (specialized agency of the United Nations, with 192 Member States), ILAE (with member organizations in more than 80 countries) and IBE (with member organizations in more than 60 countries). ILAE member organizations consist of professionals concerned with medical and scientific aspects of epilepsy, while those of IBE are concerned with social aspects and the quality of life of people with epilepsy.

In June 1997, these three partners launched the Global Campaign Against Epilepsy simultaneously from Geneva, Switzerland, and Dublin, Ireland, during the 22nd World Congress on Epilepsy. A Secretariat was established consisting of a representative from each of the three organizations, which oversees the day-to-day running of the Campaign. The Secretariat is accountable to an Advisory Board composed of two representatives of each of the three bodies. Both the Secretariat and the Advisory Board members are accountable to their respective organizations. WHO works through its regional offices and country representatives. IBE and ILAE work through their regional commissions, their resource-oriented and problem-oriented commissions, and their national member organizations.

The Campaign structure and activities are outlined in Figure 1 on page 8.

Figure 1: The Campaign structure and activities



Collaboration to increase awareness about epilepsy

Since WHO Cabinet approval in December 1999, collaboration with and support for the Campaign have been strengthened through the involvement of the Regional Offices of WHO [7]. Regular contacts are maintained with various interested clusters and departments within WHO.

Support has been provided by the Global Health Forum for Health Research for a review of the evidence base for priority setting in epilepsy research. Furthermore, the applicability to epilepsy of the common format for priority setting was determined [8].

A number of IBE/ILAE Commissions are engaged in various developmental activities for the Campaign, for example, regarding a definition of the treatment gap and outcome measures for the Demonstration Projects.

Regional conferences and declarations

As part of general awareness-raising, regional conferences on public health aspects of epilepsy were organized in the six WHO regions (Africa, the Americas, Eastern Mediterranean, Europe, South-East Asia, and the Western Pacific).

At these regional conferences, delegates of epilepsy organizations of national and international lay persons (IBE) and professionals (ILAE) met with public health experts from governments and universities and representatives from WHO headquarters and regions. As the result of intensive discussion and examination of data presented by delegates, a Regional Declaration on Epilepsy was adopted after each conference, summarizing perceived needs and proposing actions to be taken. These declarations call on governments and all health care providers to join in taking strong and decisive action to meet the objectives of the Global Campaign Against Epilepsy.

Following the European Conference, the WHO Regional Office for Europe, together with all European member organizations of IBE and ILAE, strongly supported by WHO headquarters, agreed to submit the European Declaration on Epilepsy with an accompanying White Paper to the European Parliament and European Governments[6]. This event took place in March 2001 and was followed eight months later by the establishment of a group of Parliamentary Advocates for Epilepsy, whose role is to place epilepsy on the health agenda of the European Union.

In other regions, the follow-up of the regional declarations will be tailored according to prevailing conditions.

Regional reports and country resources

A questionnaire on country resources has been developed by a group of experts, in order to map the resources for epilepsy worldwide. All IBE and ILAE member organizations and all WHO Member States have been invited to complete the questionnaire.

Reports on the implementation of the GCAE are being prepared in a number of WHO regions, which will include the data collected through the questionnaires. These documents are intended to be tools for advocacy and instruments for dialogue with governments, health care providers, donors and other partners. These reports are working papers and provide basic knowledge on epilepsy and basic facts about the epidemiological burden, as well as propose the next steps to be taken.

National activities

On a national level, the elements of the Global Campaign are adapted by the national member organizations to the needs specific to each country. The national organizations strive to implement the strategy of the Campaign through active engagement with their governments and local WHO offices. They also participate in planning the Campaign at an international level.

Technical consultative meetings

Technical consultative meetings were organized in a number of WHO regions by WHO Regional Offices in collaboration with the Campaign Secretariat. The main objectives were:

- to review the present state of epilepsy in the regions;
- to discuss regional reports on epilepsy;
- to review the implementation of the GCAE in the region, including the progress of Demonstration Projects;
- to develop a framework of action for countries.

The meetings brought together clinicians with expertise in the field of epilepsy, leaders of the Global Campaign Against Epilepsy, and senior staff from WHO [9]. In addition, a number of technical consultative meetings were organized at WHO headquarters on the progress and prospects of the Campaign, at which, for example, it was agreed that epilepsy interventions should be sustainable and provide long-term care and that the outcomes should be measured [10].

Specific activities of the Global Campaign

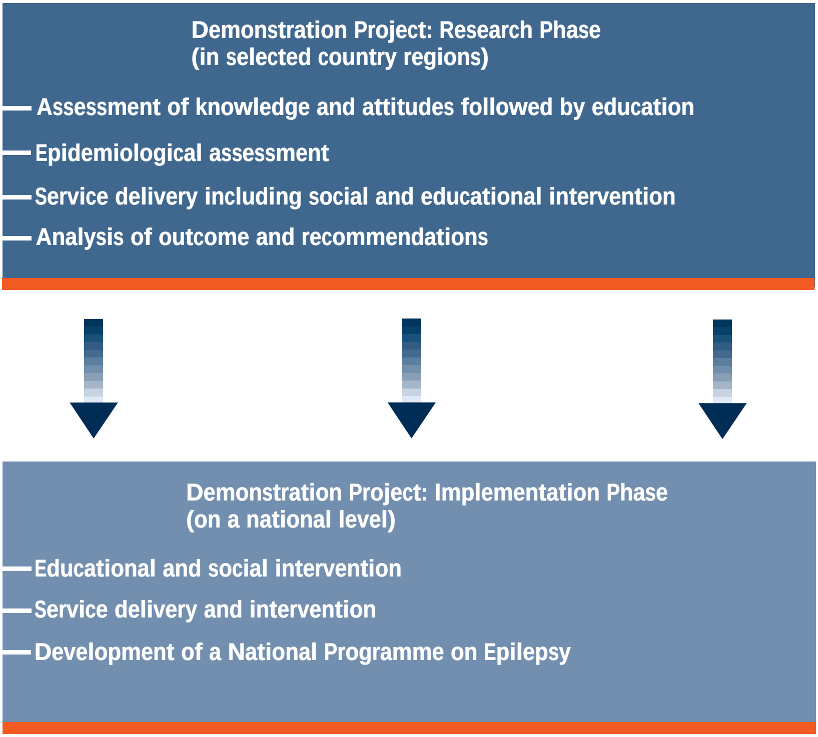
In April 1999, representatives of the three partners in the Campaign met in Geneva with epilepsy experts from industrialized and developing countries, to discuss the development and implementation of Demonstration Projects[10], which the Campaign encourages to be set up in a number of selected countries in different regions.

The counterparts of these projects at a country level will be the member organizations of IBE and ILAE, working in close collaboration with WHO country representatives. These local counterparts will be involved in raising awareness of the needs of people with epilepsy, as well as encouraging and supporting the provision of good treatment and services.

The Demonstration Projects will illustrate good practice in providing services to people with epilepsy and will be used as models of what can be achieved. When proven to be effective, similar projects will be implemented in the whole of the country in which they are situated, in neighbouring countries and, finally, globally.

Demonstration Projects start in a representative region of limited size. This is the research phase: the aim is to investigate the impact of local conditions on general strategies to improve epilepsy care. Results of the research phase are used by National Health Authorities to plan and implement services and awareness-raising about epilepsy all over the country. Results of the subsequent implementation phase are assessed in order to develop a National Programme on Epilepsy. The components of these two phases are shown in the Figure 2 on page 13.

Figure 2: Components of the two phases in the Demonstration Projects



Demonstration Project: Research Phase
(in selected country regions)

- Assessment of knowledge and attitudes followed by education
- Epidemiological assessment
- Service delivery including social and educational intervention
- Analysis of outcome and recommendations

Demonstration Project: Implementation Phase
(on a national level)

- Educational and social intervention
- Service delivery and intervention
- Development of a National Programme on Epilepsy

Demonstration Projects

Selection of location

Criteria for country selection are:

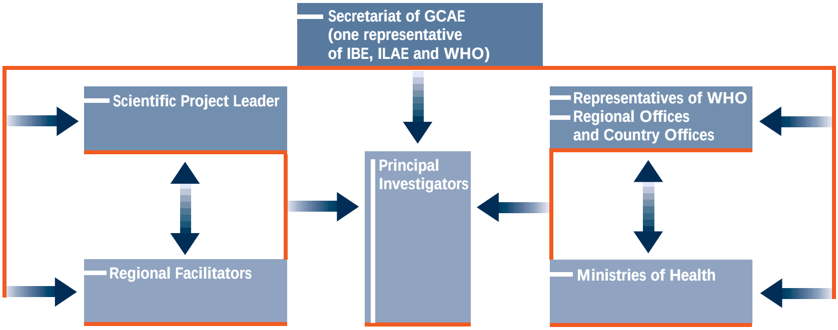
- the likelihood that results of the Demonstration Project can be utilized by other countries;
- availability of political and personal contacts;
- willingness to participate;
- availability of a WHO collaborative centre or country representative;
- presence of an IBE and an ILAE member organization, or groups that have the potential to form a member organization;
- a regular supply of basic antiepileptic drugs (AEDs);
- facility of communications.

Management structure of Demonstration Projects

The Global Campaign partners coordinate the projects, working closely with the national IBE and ILAE member organizations, other nongovernmental organizations on neurology and neuroscience, WHO Regional Offices and country offices and local ministries.

The Demonstration Projects are the responsibility of the Campaign's Secretariat, which oversees the day-to-day running of the Campaign, providing governments and other partners with sufficient, clear information and ensuring adequate funding. External funds will be used to initiate Demonstration Projects; however, such funds will not be used to pay for services or drugs, because the provision of anything except minimal outside funding for these components would be likely to indicate that the project could not be locally sustainable.

Figure 3: Outline of the management structure of a Demonstration project



Scientific supervision of the projects is delegated to a Scientific Project Leader, who liaises directly with local Principal Investigators and Regional Facilitators in to set up and monitor the projects. The Scientific Project Leader also liaises with local ILAE and IBE member organizations in order to foster local ownership and community participation and with the relevant WHO offices and Departments of Health.

The Scientific Project Leader is responsible for helping to design and evaluate the project protocols. An important aspect of the evaluation is ensuring that each Demonstration Project has sustainability built into its design and that outcomes are measurable. They are also responsible for monitoring the projects to see how they are performing, and for writing up this performance for scientific journals.

Principal Investigators have responsibility for the Demonstration Project in the country where it is held. They are responsible for constructing the project's protocol according to the guidelines of the Scientific Project Leader and local circumstances. Principal Investigators ensure that the protocol implementation keeps to its budget and timescales. The Principal Investigators are the focal points of the Campaign's relationship with the project and the people through whom information will flow. Ensuring that the project meets its outcome measures is central to their work.

Regional Facilitators, working in close relationship with the relevant WHO Regional Advisers, will support the Principal Investigators in the implementation of their projects.

An outline of the management structure of the Demonstration Projects is given in Figure 3 on page 15.

Design and activities of the Demonstration Project

In general terms, each Demonstration Project has four aspects:

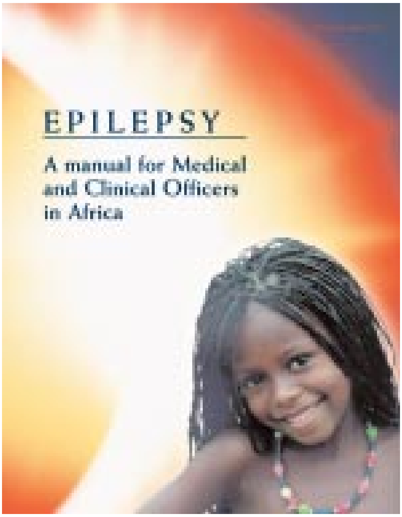
- assessing whether knowledge and attitudes of the population are adequate, correcting misinformation and increasing awareness of epilepsy and how it can be treated (Educational and social intervention);
- assessing the number of people with epilepsy and estimating how many of them are appropriately treated (Epidemiological assessment and case-finding);
- ensuring that people with epilepsy are properly served by health personnel equipped for their task (Service delivery and intervention);
- analysing the outcome and preparing recommendations for those who wish to apply the findings to the improvement of epilepsy care in their own and in other countries (Outcome measurement).

Step 1. Educational and social intervention

Incorrect perceptions about epilepsy are often the reason why people with epilepsy are stigmatized; this can be an incentive to hide the fact of having epilepsy. Symptoms from which certain persons suffer may not be recognized as a sign of epilepsy, which is a disorder for which medication is available. Both these factors are a source of underestimation when assessing the prevalence of epilepsy.

The educational and social intervention will prepare the population for the epidemiological study but will also promote a change of attitude in the community, through the following activities.

- A representative sample of the population in the area will be surveyed to assess public awareness and understanding of epilepsy and attitudes towards people who suffer from the condition.
- An educational programme to decrease social stigma, improve social relations and leisure activities, and open up realistic job opportunities will be targeted on groups of key people in the communities, such as teachers at local primary and secondary schools.
- People will be informed about epilepsy through:
    - public address systems and the media;
    - distribution of materials on epilepsy;
    - posters.
- People will be informed about international and national professional and lay organizations concerned with epilepsy.



Step 2.
Epidemiological assessment and case-finding

Correctly identifying people with epilepsy is crucial to establishing the extent of a country's treatment gap and to ensuring that appropriate treatment is offered to those who need it. It is essential that staff involved in a survey – and also health personnel who care for patients with hitherto unrecognized epilepsy – have sufficient knowledge of epilepsy, so that conflict is not created when epilepsy is diagnosed in a survey while the person is receiving treatment for another, wrongly diagnosed condition.

- At the onset of the Demonstration Project, questionnaires to assess knowledge, attitudes and practice regarding epilepsy are distributed to all health personnel in the study area; the questionnaires are self-administered.
- All physicians and a number of the primary health care personnel (village doctors) receive basic epilepsy training to correct deficiencies that were revealed by the questionnaires.
- Participation in the professional epilepsy society and support of the lay association are encouraged.
- A door-to-door survey is carried out in a representative part of the area:
    - a screening questionnaire is applied, designed to identify cases of epilepsy with convulsive seizures;
    - a village doctor then applies a diagnostic questionnaire to those patients preliminarily identified as possible cases of epilepsy with generalized tonic clonic seizures, with or without occurrence of other seizure types;
    - senior primary health care physicians then confirm the diagnosis; if there are doubts, local neurologists will be responsible for a final decision.

Step 3.
Service delivery and intervention

This stage covers quality of diagnosis, treatment, follow-up and referral networks. In order to provide appropriate treatment, activities that ensure the supply of antiepileptic drugs and facilitate their use in treatment are necessary and will be put in place if not available.

- People with epilepsy who are under the care of the team involved in the Demonstration Project will be offered the possibility of participation in the study. If their epilepsy is not active, their previous treatment will be continued; if they still have seizures, their treatment will be adjusted according to the treatment protocol of the Demonstration Project. People who are diagnosed with epilepsy and are not receiving regular treatment will be offered treatment, provided they have had at least two convulsive seizures in the previous 12 months and if they and/or their guardian are able and willing to give informed consent.
- All people who follow the protocol will be assessed separately. For each patient included in the study, a standard entry form and a follow-up form will be prepared. The protocol is based upon:
  - treatment with available first-line drugs;
  - provision of education that facilitates compliance with treatment and, if necessary, adaptation of lifestyle;
  - if seizures persist, referral to a local neurologist for reassessment and prescription of antiepileptic medication according to the findings.
- The staff involved in the Demonstration Project will receive:
  - a treatment protocol;
  - a chart to assist physicians in dealing with side-effects;
  - written instructions on evaluation and how to boost compliance.

- Patients and their families will be educated about:
  - the nature of epilepsy and its characteristics, causes and prognosis;
  - the nature and objectives of treatment, the way to use the drugs, possible side-effects and how to deal with them, the duration of treatment, and the importance of compliance.
  - general health measures, emergency treatment of seizures, and how to live with epilepsy.
- Patients and their families will be encouraged to join the local epilepsy organization for lay people.

Step 4.
Outcome measurement

Whether the Demonstration Projects are successful and provide suitable approaches for other countries to adopt will have to be confirmed by evidence. Their success or otherwise will be seen in terms of the decrease of the treatment gap and its consequences in the demonstration region.

In order to discern whether a project is achieving the desired results, its performance will be specifically measured by comparing the following before onset and after completion of project:

- the number of people with epilepsy who received a correct diagnosis;
- the number of people successfully treated;
- the social situation of people of various age groups with epilepsy
- knowledge, attitudes and practice of those interviewed at the onset.

The ultimate goal

The ultimate goal of the Demonstration Projects is the development of a successful model of epilepsy control that will be integrated into the health care systems of the participating countries and regions and, finally, applied on a global level.

Furthermore it is hoped that the lessons learnt from the Demonstration Projects will support the development of preventative measure strategies globally.

Appendix 1. More facts about epilepsy

What is epilepsy?

To understand what the Global Campaign Against Epilepsy is about, some basic facts should be known about epilepsy. For detailed information, the reader is referred to standard textbooks (e.g.[11]).

Epilepsy is the name for a group of brain disorders characterized by seizures (the word epilepsy comes from the Greek epilambanein, which means to seize or attack). Epilepsy is the most common serious neurological disorder, and can affect anyone. The seizures can occur at any time, though in some people they may be precipitated by other events. The seizures occur when recurrent episodes of brain dysfunction, with synchronized discharge of brain cells, lead to alterations in sensory, motor or other activity. Some affect localized parts of the brain and lead to partial seizures, which may consist of subjective experiences or involuntary motor activity, or both, with or without loss of consciousness. Generalized seizures can occur when both sides of the brain are involved in the synchronous discharges, and these can include tonic clonic (grand mal) seizures or subtle absences body jerks or loss of postural tone. Partial seizures may progress to generalized seizures.

Epilepsy has many causes: in some people the condition is inherited but in most it is caused by brain damage due to causes such as infections or trauma, stroke, brain tumour or development abnormalities. In many individuals the cause is never known. Some conditions can cause seizures that only occur until the provocation is removed: these are known as acute symptomatic seizures, and are not generally considered to be epilepsy.

The majority of people with epilepsy can be seizure-free. Some of them will need to continue with medication for life but, for others, the antiepileptic medication may eventually be stopped without seizures recurring.

Prevalence and incidence of epilepsy

The prevalence of epilepsy is the number of people with epilepsy in the population at any one point in time, divided by the number of people in the same population at the same time. The incidence of epilepsy is the number of people in a population who develop epilepsy during a defined period. Despite epilepsy being so common, the reported figures vary widely. The incidence is generally taken to be between 40 and 70 per 100 000 people per year in industrialized countries, with estimates of 100 – 190 per 100 000 people per year in developing countries. The prevalence is between 5 and 40 per 1000 persons[2].

The incidence and prevalence of epilepsy may vary widely because of their different causes. Parasitic, viral and bacterial infections have been suggested as important factors in the cause of epilepsy in developing countries, also infections, brain damage occurring at birth or in accidents, or other brain trauma. Some of these factors may be reduced in developing countries by improved prevention and treatment. In the affluent countries, reduction of strokes and brain tumours may lessen the incidence of epilepsy. Although it has a minor role, genetic counselling can also help to prevent certain types of epilepsy.

Epilepsy affects about 50 million people throughout the world and is especially common in childhood and in elderly people. Epilepsy affects not only the individual, but also has consequences for the family and the rest of society. A minimum of 250 million people will experience at least one seizure in their lifetime and at least 2.4 million new cases of epilepsy occur each year.

Treatments for epilepsy

In the majority of cases, epilepsy is treated using antiepileptic drugs (AEDs). Recent studies in both industrialized and developing countries have shown that up to 70% of newly diagnosed cases of children and adults with epilepsy can be successfully treated with AEDs[4], so that they are seizure-free provided they take their medicines regularly. After several years of seizure-freedom, medication can be withdrawn in 60 – 70% of people under medical supervision[12]. Of the 30% who do not become seizure-free with treatment, many will have their seizures considerably reduced. For some patients with intractable epilepsy, neurosurgical treatment may be successful.

A person is said to have active epilepsy when (with or without treatment) he or she has had at least two seizures in the previous 12 months. Once a period of five years without treatment or seizures has elapsed, a person is no longer considered to have epilepsy.

To cope with the psychological effects of having epilepsy and its consequences on quality of life, psychological and social interventions or support are often needed by people who have this disorder.

The burden of epilepsy

The impact of epilepsy on an individual is a combination of physical consequences of the seizures, the effect on the social position, and the psychological outcome of both of these. Furthermore, not only the person with epilepsy but also the family and indirectly the community are affected.

The physical hazards of epilepsy are frequently due to the unpredictability of the seizures, which may occur without warning in potentially dangerous situations. The lack of control over the seizures can be distressing, as can be the effect on onlookers.

Social exclusion can occur because of the negative attitude of others towards people with epilepsy, which can lead to isolation. In some societies, epilepsy is wrongly considered to be infectious or caused by a supernatural spirit. Children with epilepsy may be banned from school, adults may be barred from marriage, and employment is often denied, even when seizures would not render the work unsuitable or unsafe.

It has been estimated that 10% of the burden of brain and mental disorders in the world is caused by epilepsy, calculated in disability-adjusted life years (DALYs), which is very significant. This calculation includes premature deaths and the loss of healthy life due to disability[13]. However, it does not include the effects of stigma and social exclusion or their repercussions on the family[14].

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Information and contact adresses

Anyone interested in following the progress of the Global Campaign and its Demonstration Projects will be able to do so from the regular updates on the relevant web sites:
who.int/mental_health/main.cfm?s=0009
www.ibe-epilepsy.org
www.ilae-epilepsy.org).

Further information on the Global Campaign Against Epilepsy and how to help achieve the goals of the campaign in countries can be obtained from the addresses shown below.

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EPICADEC

IBE/ILAE Chapters, Friends and Commissions

Sanofi-Synthélabo

UCB Pharma

and all others who have contributed to its success.

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EPILEPSY
out of the shadows

A Global Campaign
Against Epilepsy