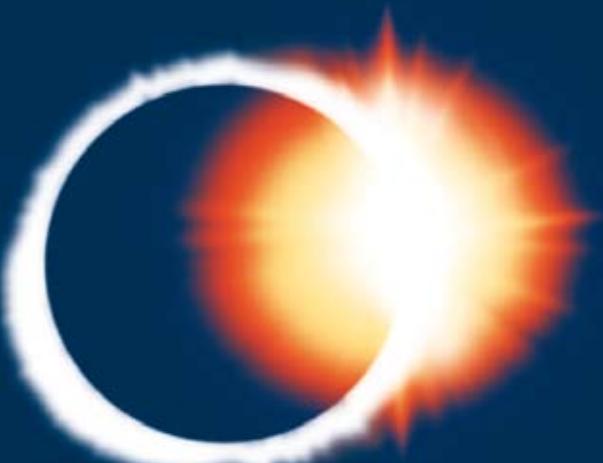


## **EPILEPSY IN THE WHO EUROPEAN REGION:**

### **Fostering Epilepsy Care in Europe**

**EPILEPSY**  
out of the shadows



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**Address requests about publications of the ILAE/IBE/WHO Global Campaign Against Epilepsy:**

Global Campaign Secretariat  
SEIN  
P.O. Box 540  
2130 AM Hoofddorp  
The Netherlands  
e-mail: [GlobalCampaign@sein.nl](mailto:GlobalCampaign@sein.nl)

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# Foreword

Epilepsy is responsible for high levels of suffering, affecting more than 50 million people worldwide, thus making it an important public health problem. In Europe 6.000.000 people are affected. Sufferers are of all ages, but epilepsy especially affects children, adolescents and the aged.

Epilepsy is the clearest example of a neurological disorder for which effective, cost-effective treatment is available. Recent studies in both the developing and the developed world show that, if properly treated, up to 70% of people with this condition could live productive and fulfilling lives. Yet, in developing countries, up to 90% or more of people with this condition are excluded from care and consequently remain in the shadows of the so-called treatment gap. One reason for this exclusion is the social stigma attached to epilepsy. The stigma of epilepsy affects the education of children and young people and the employability of adults.

The solutions to these problems are too complex to be solved by individual organizations. Therefore, the three leading international organizations working in epilepsy - the International League Against Epilepsy (ILAE), the International Bureau for Epilepsy (IBE), and the World Health Organization (WHO) - have joined forces in the ILAE/IBE/WHO Global Campaign Against Epilepsy (GCAE) in order to bring epilepsy 'out of the shadows'.

The Campaign aims to assist governments worldwide to ensure that the diagnosis, treatment, prevention and social acceptability of epilepsy are improved.

The strategy has two parallel tracks: raising general awareness and understanding of epilepsy; and supporting national Ministries of Health to identify the needs and to promote education, research, training, prevention, treatment and care services.

The Campaign has been officially launched, and activities are under way in over 70% of the countries of the European Region. The collaboration between IBE, ILAE and WHO has given the Campaign the opportunity to build a framework for concerted action on global, regional and national levels to raise awareness and diminish the treatment gap.

The European activities show that partnerships between WHO and nongovernmental organizations are clearly the way forward for bringing epilepsy 'out of the shadows'.

Benedetto Saraceno  
Director, Department of Mental Health and Substance Abuse  
World Health Organization

# Preface

In Europe, at least 6 million people have epilepsy, and 15 million Europeans will have one seizure at some time in their lives. Nevertheless, in some countries of Europe, epilepsy is not recognized as a brain disorder, and up to 40% of people with this condition may be untreated - the treatment gap.

Epilepsy is a treatable condition and relatively cheap medication is available. Professionals who treat people with epilepsy, however, often do not have sufficient specialized knowledge of the condition, and, in some countries, antiepileptic drugs are not always available or are not affordable and diagnostic facilities are lacking or are inadequate. It has been estimated that the 6 million people with active epilepsy in Europe cost over € 20 billion per year, and despite this, very few European countries have national plans for managing the disorder.

Epilepsy continues to take its toll, impairing the physical, psychological and social functioning of those affected and equally causes serious psychological, social and economic consequences for their families. People with epilepsy, and sometimes their family members, are often stigmatized, generating a hidden burden which discourages them from seeking the diagnosis and care they require. Stigma leads to discrimination and it is not uncommon for people with epilepsy to be denied access to education. Discrimination of people with epilepsy in the workplace is not unusual.

The 6 million people with epilepsy in Europe deserve the right to be treated appropriately. They want the treatment to be available, accessible, affordable and of good quality as this is their human right.

The 6 million people with epilepsy in Europe want appropriate information about their condition, the restrictions and the possibilities.

The 6 million people with epilepsy in Europe want to go to school, to obtain employment and to develop relationships, like any other European man or woman.

The 6 million people with epilepsy in Europe want the misconceptions, prejudice and subsequent stigma to be eliminated through public education programmes.

The 6 million people with epilepsy in Europe want to bring epilepsy "out of the shadows".

The ILAE/IBE/WHO Global Campaign Against Epilepsy is working towards this goal. Let's bring epilepsy out of the shadows, on behalf of and with the 6 million people with epilepsy in Europe.

This regional report for Europe provides a panoramic view of the present epilepsy situation in the Region, outlines the initiatives taken by the Global Campaign partners to address the problems, define the current challenges and offers appropriate recommendations. It is an advocacy tool and an instrument for dialogue with governments, consumer associations, nongovernmental organizations, academic institutions and development partners. We believe that it would help countries in developing activities to combat stigma, restore dignity and reduce the treatment gap for people with epilepsy in the region.

Hanneke M. de Boer,  
Co-ordinator Global Campaign Against Epilepsy  
SEIN - Epilepsy Institute in the Netherlands

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\*See tribute on page 7

# Tribute

It is with deep regret that we have to inform the readers of this report of the passing away of Dr. Leonid L. Prilipko on 23 April 2007.

Dr. Prilipko was born in 1945 in Baku, Azerbaijan former Republic of the USSR. He studied and worked in Moscow until 1986. During this period he had the opportunity to work abroad as a visiting scientist e.g. in Chicago - USA, Prague - Czech Republic, Irkutsk - Siberia (USSR) and Lucknow - India.

In 1986 he moved to Geneva to start working with the World Health Organization as the Senior Medical Officer in the Division of Mental Health. In the Department of Mental Health and Substance Abuse his last function was Programme leader for Neurological diseases and Neurosciences.

Dr. Prilipko was a key actor in the establishment of the ILAE/IBE/WHO Global Campaign Against Epilepsy to bring "Epilepsy out of the Shadows". He worked tirelessly to raise awareness of epilepsy in all WHO regions, and within WHO itself. He was the driving force behind most of the Regional Conferences on Epilepsy and the development of the Regional Declarations. He was

instrumental in the success of the Demonstration Projects for instance in China and Brazil, and also initiated a project in Georgia. He once said: "My dream is to have made a difference for people with epilepsy by the time I retire". He retired in September 2005.

The following sentence is from a letter of condolence sent by the First Lady of Georgia, Sandra Roelofs: "It is he who started one of the broadest and most important global campaigns against epilepsy, and this is why millions worldwide should be grateful to this noble man".

Leonid Prilipko was a true friend, an ambassador for epilepsy, with respect for all people from all cultures. He thought of solutions rather than problems and conflicts and this was key in keeping the collaboration between WHO, IBE and ILAE going strong.

The achievements of the Campaign will remain as testament to his dedication.

Hanneke M. de Boer  
Global Campaign

# Abbreviations

CI	confidence interval
CIS	Commonwealth of Independent States
CT	computed tomography
EEG	electroencephalogram
EFNS	European Federation of Neurological Societies
EU	European Union
EUCARE	European Concerted Action and Research in Epilepsy
EURAP	European Registry of Antiepileptic Drugs during Pregnancy
EUREPA	European Epilepsy Academy
GCAE	Global Campaign Against Epilepsy
GDP	gross domestic product
IBE	International Bureau for Epilepsy
ILAE	International League against Epilepsy
IQ	intelligence quotient
MRI	magnetic resonance imaging
NGO	Non-Governmental Organizations
SEIN	Stichting Epilepsie Instellingen Nederland (SEIN: Epilepsy Institute in the Netherlands)
SMR	standardized mortality ratio
WHO	World Health Organization

# Background information on the European region

The European Region of the World Health Organization comprises 53 countries, covering the usual 'European' countries west of the Ural but also the former Soviet Union Republics including the 5 Central Asian Republics. It borders seas on three sides, and Syria, Iraq, Iran, Afghanistan, Pakistan, Mongolia and China on the South side. It has a population of some 850 million people, and about 45 official languages are spoken in its 53 Member States. The Region is very unequal economically, with a strong gradient from a poor East to a very rich West, especially the 27 countries of the European Union. The GNI per capita (World Bank, 2008) varies from US\$ 600 (Tajikistan) to US\$ 84.890 (Luxembourg). Health wise, life expectation ranges for men from 58.9 years in the Russian

Federation to 79.5 years in Iceland. In women it ranges from 69.8 years in Turkmenistan and 71.7 years in Moldova to 83.9 years in France and Switzerland.

The European Union (EU) is a grouping of twenty-seven independent states and founded to enhance political, economic and social co-operation and integration. The European Commission has had competence in health only since 1993 and this is limited to public health as national health systems were excluded. The Treaty of Amsterdam, which entered into force on 1 May 1999, gave the European Parliament a new remit and competency for health promotion.

**Table 1: Countries (in alphabetical order) by World Bank income categories**

Low income	Lower middle income	Upper middle income	High income
Kyrgyz Republic	Albania	Belarus	Andorra
Tajikistan	Armenia	Bulgaria	Austria
Uzbekistan	Azerbaijan	Kazakhstan	Belgium
	Bosnia and Herzegovina	Latvia	Croatia
	Georgia	Lithuania	Cyprus
	Republic of Moldova	Montenegro	Czech Republic
	Turkmenistan	Poland	Denmark
	Ukraine	Romania	Estonia
		Russian Federation	Finland
		Serbia	France
		The former Yugoslav Republic of Macedonia	Germany
		Turkey	Greece
			Hungary
			Iceland
			Ireland
			Israel
			Italy
			Luxembourg
			Malta
			Monaco
			Netherlands
			Norway
			Portugal
			San Marino
			Slovakia
			Slovenia
			Spain
			Sweden
			Switzerland
			United Kingdom

In the following chapters, studies and practices on epilepsy in Europe are described according to World Bank income category. Most countries are in the upper-middle and high-income categories, the latter are mostly EU Member States. Norway and Iceland are part of the associated European Free Trade Agreement, allowing them to participate in the European single market without joining the EU. Switzerland has its own bilateral economic agreement with the EU. Only three countries in the European Region are low income countries, all Central Asian Republics (Table 1).

### **Health and health care**

Standards of health care in general and epilepsy care specifically vary considerably between European countries. These variations are mainly due to differences in the governance of health care,

funding, resources such as hospitals and workforce and service delivery. In most countries in the region a mixed system of public and private funding and/or insurance, service delivery, disability programmes and social security share the responsibility.

In many European countries health care systems are being re-structured, and the present systems are shifting towards an emphasis on choice and market driven systems, while attempting to preserve equity and solidarity. The former socialist countries are diversifying from their former centralized and state provided care, which was in principle comprehensive, free of charge and available to all, towards systems comparable to western models of health care, but struggling to implement within the available resources (1).

# 1. Introduction

Epilepsy has been spoken and written about for over 4.000 years. Through the centuries, many misconceptions about the condition have been conveyed based mainly on the popular culture of a particular era or in a particular part of the world. Leon Eisenberg, from Harvard Medical School in Boston, stated: "Epilepsy is an ancient disease that has been "explained" for as long as it has been perceived. Its manifestations invite arcane theories of its causes and its meanings. Seizures are dramatic, public and frightening. They occur with unpredictable frequency in unexpected places. The forced cry, the loss of consciousness, the fall, the twitching and the foaming at the mouth, they all suggest possession by the spirit".

People with epilepsy are being looked upon as "being chosen" or as "being possessed" depending on the popular belief of that moment or place, with subsequent consequences for treatment and for the societal attitudes towards them. In many parts of the world there is a grave social stigma attached to epilepsy. People may believe that epilepsy is contagious and hesitate to help or touch the person who has fallen in a seizure, even when this happens in hazardous places, like in the water or near an open fire. The stigma associated with epilepsy also has a great influence on the education of children and young people who have the condition and quite often leads to the isolation of these youngsters.

Everywhere epilepsy is a hidden condition, both in the developed and the developing world. As it was once stated "The history of epilepsy can be summarised as 4.000 years of ignorance, superstition and stigma, followed by 100 years of knowledge, superstition and stigma".(2)

Epilepsy is a condition characterized by the recurrent (two or more) epileptic seizures unprovoked by an immediate identifiable cause. An epileptic seizure is a clinical manifestation presumed to result from an abnormal and excessive discharge of a set of neurons in the brain. The clinical manifestation consists of sudden and transitory abnormal phenomena which may include alterations of consciousness, motor, sensory, autonomic or psychic

events, perceived by the patient or by an observer. Epileptic seizures are the most common positive symptoms of a compromised brain. One in twenty of people (or 5% of the general population) who live a normal life span can expect to have at least one epileptic seizure at some point in life. Virtually any injury or abnormality of the brain can cause irritation of vulnerable neurons to produce an extraordinarily wide variety of positive symptoms that are epileptic seizures. The nature of these symptoms depends on the parts of the brain involved in the disturbance.

Epilepsy is the most common serious brain disorder world wide. It has no age, racial, geographic or socio-economic boundaries. The prevalence of epilepsy in Europe is 8.2 per 1000 people (figure 1), thus around 6.000.000 people in Europe currently have epilepsy whilst 15.000.000 people will have

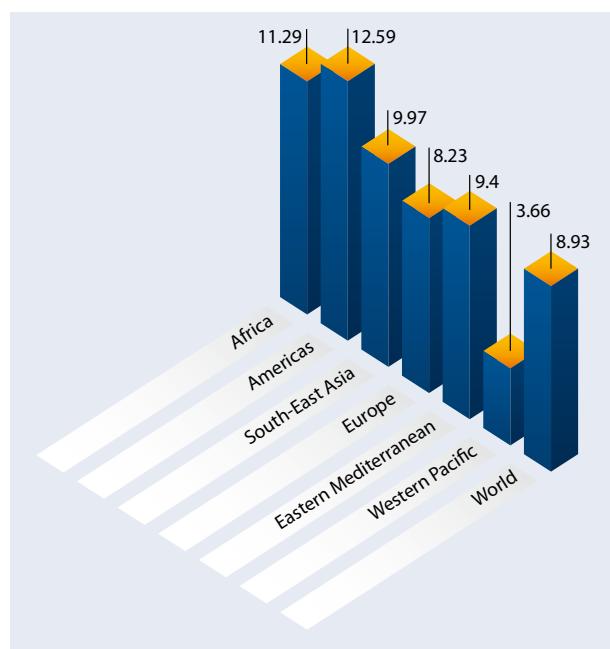


Figure 1 Mean number of people with epilepsy per 1000 population in WHO Regions and in the world  
(Atlas: Epilepsy Care in the World 2005)

had epilepsy at some time in their lives (1). Studies of the prevalence of epilepsy show that 1 out of every 20 or 30 persons in parts of the world with poor health conditions has epilepsy; in other parts, such as Europe, the prevalence is about 1

out of every 100 to 150. Thus a typical family physician in Europe will have 10-20 persons with epilepsy among his or her patients and will therefore not consider epilepsy a priority and may not keep track of the latest developments in the field of epileptology.

Epilepsy can be treated very effectively with antiepileptic medication. Up to 70% of patients may become seizure free (about 60% with the first drug and a further 10% after further attempts). In 60% of cases the treatment can be withdrawn after 3-4 years of seizure freedom without seizure recurrence.

Older and newer drugs are likely to have similar effects in terms of seizure control. Yet, despite the availability of this effective and non-expensive treatment, there is an estimated treatment gap of 40% (1) in Europe.

Discrimination against people with epilepsy in the workplace and with respect to access to education is not unusual. Violations of human rights are often more subtle and include social ostracism, being overlooked for promotion at work and denial of the right to participate in social activities taken for granted by others in the community.

## 2. Epilepsy in the European region

### 2.1 Epidemiology

Epidemiology is the medical discipline which studies the dynamics of a medical condition in the general population. It is concerned about the numbers of people with the condition, who are at risk and what is the outcome of the condition. It allows for the rational planning of health delivery.

Better understanding of the epidemiology of epilepsy is a prerequisite for improving epilepsy care. However, the epidemiological study of epilepsy remains difficult for a number of reasons. When suspected, epilepsy is not always easy to diagnose. Many epidemiological studies on epilepsy have been published, but the lack of rigorous definitions of the disease, differences in the methods of case ascertainment, classifications of seizures or epileptic syndromes and evaluation of risk factors hamper meaningful comparisons.

#### Incidence studies

Incidence data are particularly limited, especially from low and lower middle income countries. They are usually divided into those of recurrent

unprovoked seizures and those that include first seizures, acute symptomatic seizures or isolated seizures. Age-adjusted incidence rates are usually expressed per 100 000 persons per year.

The age-adjusted incidence rates of first epileptic seizures or newly diagnosed epileptic seizures in Europe range from 18.9 to 69.5 (3-6). In such studies, usually both provoked and unprovoked seizures are considered and sometimes single or isolated seizures. These studies are difficult to compare because the inclusion criteria are often different. Two surveys of newly diagnosed seizures in the Gironde department in France and in Geneva Canton in Switzerland, conducted with the same methods and including acute symptomatic seizures, recurrent unprovoked seizures and single seizures, gave similar figures: 69.5 and 69.4 per 100 000 inhabitants (7,8).

The incidence rates of epilepsy in Europe vary between 28.9 and 47 per 100 000. The lowest rates have been observed in studies in which only recurrent (also known as asymptomatic or afebrile) seizures were included (9,10).

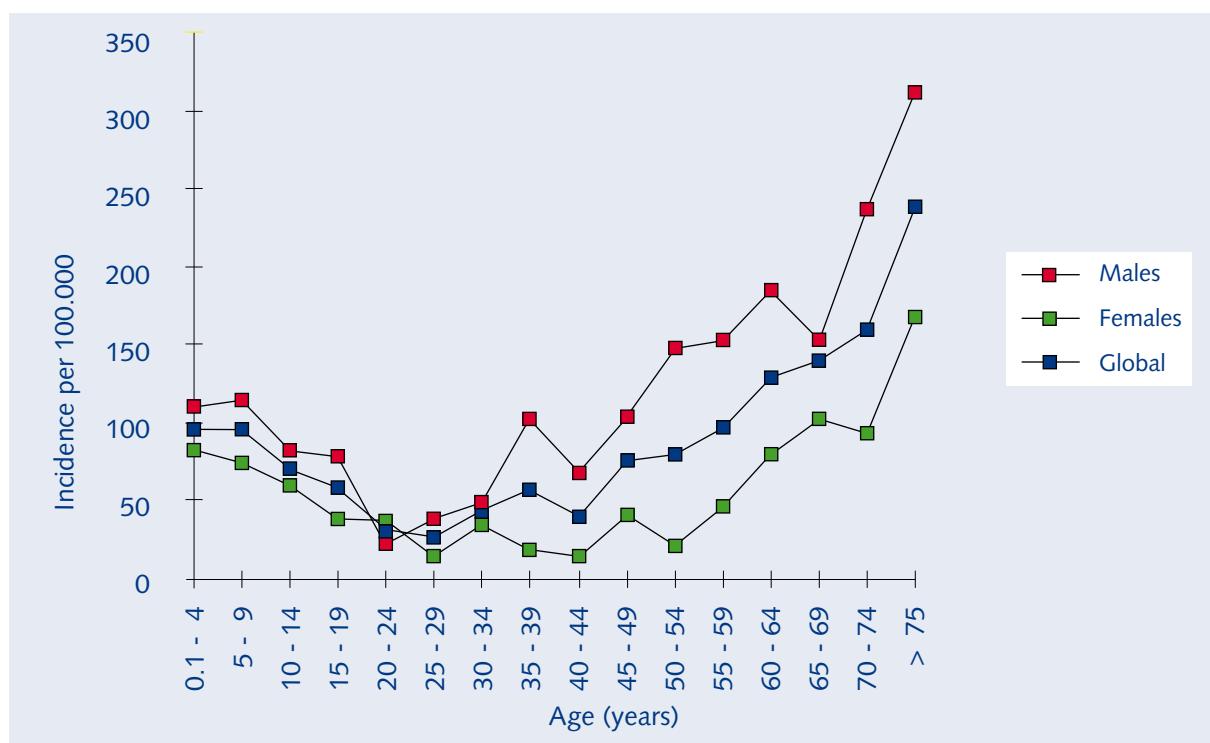


Figure 2 Age-specific incidence of epilepsy

Data from Estonia (11) revealed that both the crude and the age-adjusted incidence rates of epilepsy in adults (aged  $\geq$  20 years) were 35 per 100 000. The crude incidence rates for adolescents and adults (aged  $>$  14 years) in several areas of eastern Siberia were similar: 25-30 per 100 000 (12).

The relative age-specific incidence rates are similar in all studies. Many studies have been conducted specifically in children, excluding neonates, with different case ascertainment methods, with a mean incidence rate 70-80. The age distribution of the incidence of epileptic seizures and epilepsy is bimodal, with two peaks of frequency: in childhood and in the elderly (figure 2). There is evidence of a decreasing incidence in children with improved prenatal care and immunization programmes, with a simultaneous increase in the elderly related to increased life expectancy and improved survival of patients with cerebrovascular disease.

Population-based studies indicate that the incidence and prevalence of seizure disorders increase exponentially after the age of 60 years (13-15). The annual incidence is about 100 seizures per 100 000 persons over 60 years of age, and the elderly are now the fastest growing group of patients with epilepsy, with the highest incidence in the general population (16).

Four studies addressed the frequency of status epilepticus (17). The incidence rate varied from 9.9 to 17 per 100 000, which is much lower than those observed in the USA. The variation among the studies can be explained by the definition of status and the inclusion of myoclonic post-anoxic encephalopathies in the studies done in USA.

### Prevalence studies

Studies of the prevalence of epilepsy can be used to assess various aspects. The lifetime prevalence is the number of individuals who ever had an epileptic seizure, divided by the mid-year population.

Prevalence is the number of people with a given condition in the population at a given time. Knowledge about the prevalence of epilepsy is important as it allows for the estimation number of

people affected by the condition and this is essential for the planning of health delivery for people with epilepsy. It estimated that the prevalence of active epilepsy in Europe lays between 4 and 10 per thousand people.

Point prevalence gives the number of people with 'active' epilepsy divided by the mid-year population. 'Active epilepsy', as defined by the ILAE Commission on Epidemiology and Prognosis, covers only people who have had recurrent seizures within the 5 years prior to the study or who were on antiepileptic drugs on prevalence day. Provoked seizures or isolated seizures are excluded.

All rates in prevalence studies are expressed per 1000 people in the population. For instance, the overall lifetime prevalence in Norway ranges from 3.5 to 10.7. In children, the lifetime prevalence ranges from 4.4 to 6.8 (18).

Data on prevalence are available from Azerbaijan, Estonia, Lithuania and the Russian Federation, although differences in methodology and study populations make comparisons difficult. The prevalence rate in the Nakhchivan area, Azerbaijan, was 5.9 per 1000 population (S. Magalov, personal communication, 2004). The age at onset of the disease was below 20 years in 80.8% of cases. The crude and age-adjusted prevalence rate of active epilepsy in an adult population in Estonia was 5.3 per 1000 (11). The prevalence of active epilepsy in children (aged 0-15 years) was estimated in Kaunas, Lithuania, to be 4.2 (3.4 when age-standardized) per 1000 (19).

An epidemiological study of active epilepsy in people over 14 years is being performed in eight European and (Asian) sites of the Russian Federation in people over 14 years. It has been completed in Moscow and in Irkutsk and Ulan-Ude in eastern Siberia. The crude prevalence rate of epilepsy increased from the western to the eastern regions, from 2.2 in Moscow to 4.2 per 1000 in Irkutsk. The prevalence was relatively consistent within the European part (2.2-3.4 per 1000) and within Asian (4.1-5.0 per 1000). Late-onset epilepsy was more frequent in the European than in the Asian region (20, 21).

The prevalence of active epilepsy in urban and rural areas of Turkey has been studied in adult and paediatric populations. The crude prevalence rate was 7.0 per 1000 (8.8 in rural and 4.5 in 1000 in urban areas), with a mean age at onset of 12.9 years (22). The crude prevalence rate of active epilepsy in another rural area (Silivri) was even higher, 10.2 per 1000 (21). Another study (23) showed that the lifetime prevalence rate in a rural area of Istanbul was 0.8%, with partial epilepsy in 41.2% of cases and generalized epilepsy in 47.0%. The prevalence of epilepsy in children 0-16 years was also 0.8%; 55.2% of patients had generalized epilepsy, 39% partial and 5.8% unidentified (24).

These studies show that the epidemiological characteristics of active epilepsy in different countries in the Region are similar. Overall, the data from the Russian Federation show trends similar to those in western Europe, although the studies in the European part of the Russian Federation indicate a lower prevalence than in western Europe. The rates are higher in rural areas compared to urban areas.

#### **Morbidity studies**

The risks for morbidity and accidents in patients with epilepsy was analyzed in a European prospective multicentre study with patients in England, Estonia, Germany, Italy, the Netherlands, Portugal, the Russian Federation, Slovenia and Spain (25). Although based on referred patients rather than being population-based, this is the most comprehensive, informative study of its kind so far. Children and adults with epilepsy ( $n = 951$ ) and matched controls ( $n = 904$ ) were followed prospectively for up to 2 years (25). By that time, 270 accidents had been reported by 199 patients, with 149 accidents reported by 124 controls. The probability of accidents was moderately higher among patients than among controls, with 27% of patients and 17% of controls having suffered an accident by 2 years (26).

About one-fourth of the accidents in patients with epilepsy were seizure-related. The commonest injuries were contusions and wounds, followed by abrasions, fractures and brain concussions. The greatest increase in risk over that of controls was for

concussion, the risk being increased 2.6-fold. Except for brain concussion, most of the accidents occurring in patients with epilepsy and in the controls were trivial, and their frequency tended to decrease significantly after exclusion of seizure-related events. Morbidity was analyzed in the same cohort (27). An associated disability was present from the onset of the study in 13% of the patients with epilepsy and 2% of the controls. During follow-up, 68% of patients and 56% of controls ( $p < 0.0001$ ) reported an illness, which was seizure-related in 30% of the cases. The commonest complaints by the patients were disorders of the nervous system (headache, seizures and dizziness) or of the ear, nose and throat. Such complaints were commoner among patients than controls, and there was a significant correlation between the number of illnesses and seizure frequency (25). Patients with epilepsy were also admitted to hospital for an illness more often than controls (24% and 6%, respectively); however, the risk for illness among epilepsy patients was significantly reduced when seizure-related events were excluded.

#### **Mortality studies**

The epidemiological approach to estimating mortality is difficult to use in the case of epilepsy, as it depends on the accuracy of information about the cause of death and the methods used. Many epidemiological studies have established beyond doubt that patients with epilepsy have significantly higher mortality than the general population. This has been shown in large population-based cohort incidence studies as well as in more selected populations (28). Thus it is understandable that the main concern of most people with epilepsy and their families is that the seizures will have fatal consequences.

The standardized mortality ratio (SMR) is the ratio of the observed number of deaths in a population with epilepsy to that expected from age- and sex-specific mortality rates in a reference population. Population-based studies provide death rates and SMRs that are representative of persons with epilepsy in general. Both prospective and retrospective incidence cohort studies are consistent in identifying increased mortality in patients with epilepsy. The SMRs in

these populations ranged from 1.6 to 5.3 in children and adult populations, with higher SMRs in studies of children and in some other populations.

Two European population-based studies have been conducted on mortality among children with epilepsy. In a prospective study (29) of 124 children with epilepsy in the United Kingdom, nine (7%) had died by the age of 28. Another project (30) studied the long-term prognosis of 245 (61% incident, 39% prevalent) children with epilepsy in Finland. Of the 220 patients with available data, 44 (20%) had died 30 years after diagnosis, yielding a mortality rate of 6.2 per 1000 patient-years (95% CI, 5.7-6.7).

While the mortality among persons with epilepsy in population-based studies is two to three times higher than that in the general population, this is largely due to the cause of the epilepsy, such as a brain tumour or cerebrovascular disorder. In contrast, fatalities among patients with chronic, refractory epilepsy are more often seizure-related and are in most cases sudden and unexpected. Although the mechanisms are unknown, sudden unexpected death in epilepsy has generally been reported to occur in conjunction with a generalized tonic-clonic seizure. In patients with chronic refractory epilepsy, sudden unexpected death may account for as much as 25-65% of all deaths (31-37).

## ■ 2.2 Management

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### Introduction

Epilepsy can be treated with antiepileptic drugs. During the last 15 years there has been a dramatic increase in the therapeutic options available (table 2)

Antiepileptic medicines	Year of introduction
Phenobarbital	1912
Phenytoin	1939
Ethosuximide	1955
Primidone	1960
Carbamazepine	1965
Valproate	1970
Oxcarbazepine	1990
Lamotrigin	1991
Gabapentin	1994
Topiramate	1995
Levetiracetam	2000
Pregabalin	2005
Zonisamide	2007
Vigabatrin	1989*
Tiagabine	1996**
Felbamate	1994*

*Table 2: Antiepileptic Drugs currently available*

\* Due to serious side effects the use has been restricted (mostly for infantile spasms)

\*\* Marketed at a very low scale

The success rate of both the older and newer drugs have been very similar and led to seizure freedom for up to 70% of patients, however, the newer drugs may have less side effects and lead to a better quality of life of patients.

The provision of adequate treatment and care for children and adults with epilepsy is a major concern for epileptologists. Standards of care vary considerably across countries within Europe, and, even where the standards of diagnosis, therapy and rehabilitation are high, as in middle and high income

countries of the Region, the care of many patients remains inadequate because of lack of access.

Several groups of countries can be differentiated. Czech Republic, Hungary, Poland, Slovakia and Slovenia, have traditions inherited from the Austro-Hungarian Empire and which are shared with western European countries like Austria and Italy.

After the dissolution of the Soviet Union, Armenia, Azerbaijan, Belarus, Estonia, Georgia, Kazakhstan, Kyrgyzstan, Latvia, Lithuania, the Russian Federation, Tajikistan, Turkmenistan, Ukraine and Uzbekistan were confronted with a particularly difficult situation after the collapse of the central health system and were obliged to build up their own health systems.

Albania, Bulgaria, Croatia, Montenegro, Romania, Serbia and the Former Yugoslav Republic of Macedonia form a third group whilst Estonia, Latvia, Lithuania and Finland have different characteristics yet again, with their Hanseatic trade heritage.

The Commission on European Affairs of the ILAE drew up guidelines for standards of medical care appropriate to the whole of Europe in 1997 (38). The guidelines were essentially a summary of the consensus reached on contemporary expectations concerning evaluation and treatment, regardless of the health-care characteristics and real possibilities for provision in individual countries. One year later, a conference in Heidelberg, Germany, organized under the auspices of the Global Campaign, led to a questionnaire-based evaluation of the features of epilepsy management (39).

### **The treatment gap**

The gap between those who require treatment that receive it and those who do not, is very large. For example, in the Nakhchivan area of Azerbaijan, only 9.7% of persons with epilepsy were receiving treatment. In Estonia, about 22% of all persons with epilepsy did not take antiepileptic medication (11). In the Russian Federation, the majority of patients with active epilepsy were under treatment, but a substantial number of patients were receiving suboptimal treatment. This was considered to

explain the high percentage of persons officially recognized as disabled (40-45% compared with 10% in the general population) and the long duration of active epilepsy ( $\pm$  10 years). About 35% of patients had had the condition for more than 15 years (40).

The provision of epilepsy treatment and care across Europe was investigated in a survey of the European ILAE chapters by the Commission on European Affairs (41). The purpose of the survey was: To assess the needs and resources available in the provision of basic epilepsy care across Europe. A mailed questionnaire was used, the European Epilepsy Services inventory (EESI). The EESI was sent to all 36 European chapters of the International League Against Epilepsy (ILAE), and responses were obtained from 32, a response rate of 89%. A number of chapters completed the questionnaire on the basis of national or international publications (42-48).

The survey showed that, despite large national and regional variations in the provision of epilepsy care, problems are similar across Europe.

The problems were more pronounced in Commonwealth of Independent States (CIS) countries but even countries with the best epilepsy care lacked comprehensive care and epilepsy specialists, with stigmatization and social problems and lack of knowledge even within the medical profession.

Lack of epidemiological data was one of the commonest problem areas.

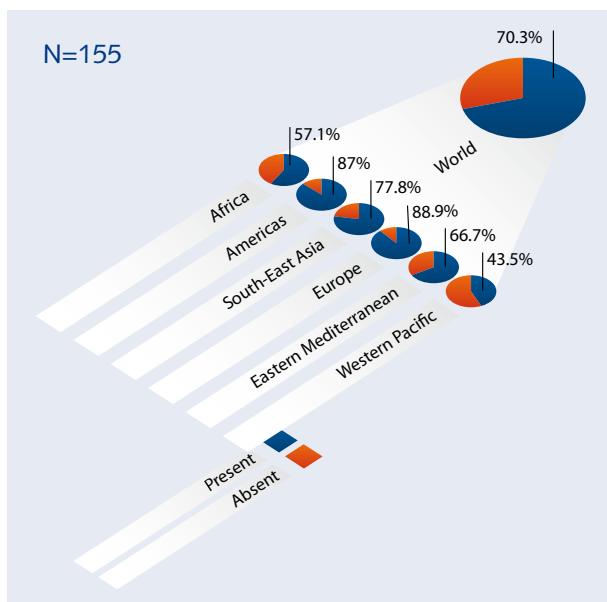
Furthermore the survey results showed a wide range in the numbers of physicians and specialists involved in epilepsy care across Europe, with a clear trend towards higher numbers of neurologists, paediatricians and paediatric neurologists in countries that used to be under the influence or were integral parts of the former Soviet Union.

Most patients are seen by a neurologist, and fewer are cared for by an epileptologist in most countries. Epileptology has become a speciality in its own right in a considerable number of countries. More than half the eastern European countries reported the existence of epilepsy specialists.

Epilepsy specialists and diagnostic facilities are well represented for clinical electrophysiology, but there is still poor access to morphological and functional neuro-imaging and limited use of epilepsy-targeted working methods. Epileptological subdivisions of neurological departments exist in several central and eastern European countries, and child epileptology is represented in several departments. Some have comprehensive epilepsy programmes, but economic constraints impede rehabilitation efforts, especially with regard to employment.

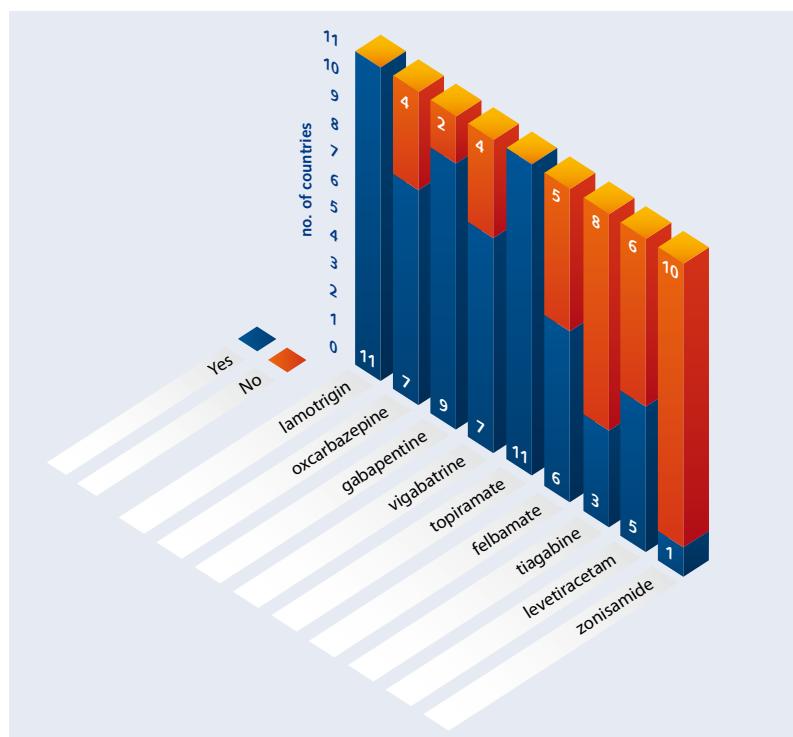
In 2001/2002, a detailed questionnaire on country resources for epilepsy was sent to the chapters of ILAE, under the auspices of WHO, ILAE and IBE within the framework of the Global Champaign Against Epilepsy. The survey focussed on the prerequisites for and the provision of basic epilepsy care, i.e. diagnosis and first-line treatment (49).

The number of epilepsy specialists in Europe is highest of all WHO Regions (figure 3). The smallest number of neurologists in a western European country was three neurologists per 1 million inhabitants and the highest 71 per 1 million, i.e. a variation in the density of neurologists across western Europe by a



*Figure 3: Countries with epilepsy specialists in WHO regions and the world (Atlas: Epilepsy Care in the World 2005)*

factor of almost 24. The wide range in the number of physicians in general and of specialists relevant to epilepsy patients in particular implies that many patients are treated by physicians with limited knowledge of epilepsy, even if most patients are seen by a neurologist.

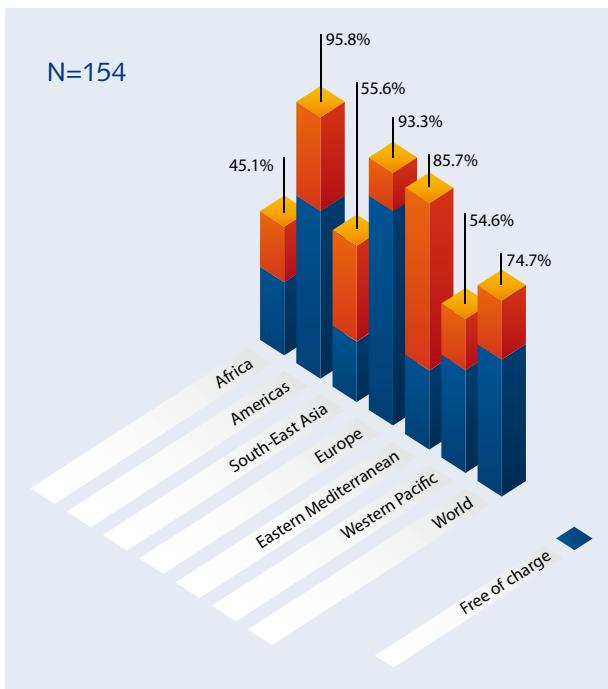


*Figure 4: Availability of antiepileptic drugs in a selected group of countries in the European region*

The care of cognitively impaired patients with epilepsy in particular is spread across various specialities, including general practitioners, neurologists, paediatric neurologists, paediatricians and psychiatrists.

Most antiepileptic drugs were available all over Europe. The economic availability of these drugs for patients was, however, more difficult to describe, as several systems of reimbursement exist. In high income countries, the commonest systems were 100% reimbursement of all registered antiepileptic drugs; a variable percentage of reimbursement, from 100% for older drugs to much less for newer drugs; and a general percentage of reimbursement up to an annual 'ceiling' for total drug cost for each patient.

Antiepileptic drugs, including the newest ones, are relatively widely available in most countries in the Region (figure 4). Social insurance for reimbursement of the new drugs is variable in these countries: in almost half of the countries, the State reimburses 90-100% of the expense, but in the other half reimbursement is much lower.



*Figure 5: Therapeutic drug monitoring in WHO regions and the world ((Atlas: Epilepsy Care in the World 2005)*

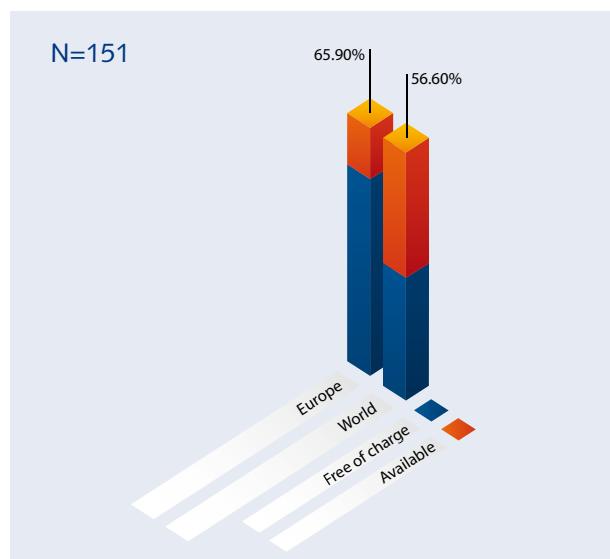
Outpatient visits were free of charge in one-half of

the countries, while there was a patient fee in the other half. Hospitalization and investigations are free of charge in most high income countries in the Region.

Halfway through the last century it became technically possible to see whether failure of medication was due to not taking the prescribed medication or because of metabolic reasons which meant that the blood levels of the drug were not as expected. As can be seen from figure 5, therapeutic drug monitoring is nowadays available in more than 90% of the European countries.

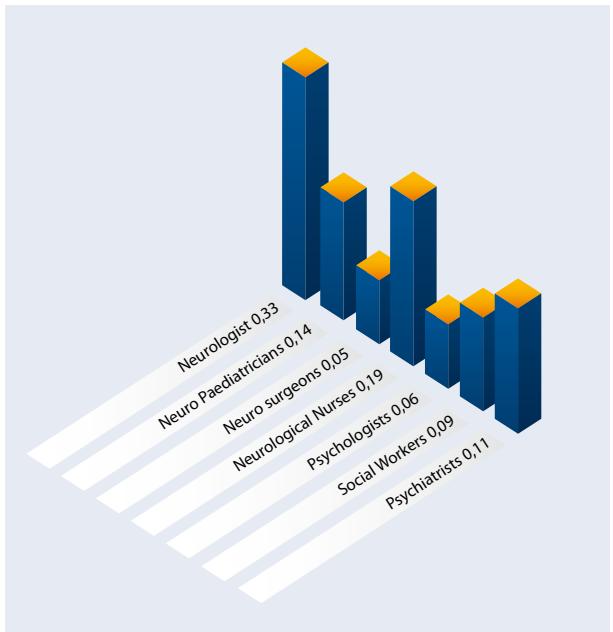
### Comprehensive care

Comprehensive care, in which medical intervention (e.g. antiepileptic drug treatment or epilepsy surgery) is linked to non-medical intervention (e.g. counselling, psychosocial assistance (figure 6) and rehabilitation), is an important part of epilepsy management (figure 7).



*Figure 6: Neuropsychological Services in different income groups of countries*

Epilepsy-related psychological problems (e.g. perceived stigma), social restrictions, vocational limitations and impaired social contacts may persist despite medical success. Coordination of the services needed, such as psychological referral and vocational rehabilitation, is best undertaken by a multidisciplinary team. Such comprehensive care teams commonly consist of a neurologist, a



*Figure 7: Number of health professionals per 100,000 population involved predominantly in epilepsy care in the WHO European region*

psychologist, an epilepsy nurse, a social worker and a psychiatrist. In the survey by the ILAE Commission on European Affairs - Sub-commission on European Guidelines 1998-2001 (41), all the high income European ILAE chapters reported the existence of such multidisciplinary teams, although the number of teams per 1 million inhabitants ranged from 0.36 to 3.3, indicating that the provision of comprehensive care varies considerably. In countries with the lowest availability of comprehensive epilepsy teams, one such team would have responsibility for about 18 000 patients, about 6000 of whom would have pharmaco-resistant epilepsy.

### **Surgery**

Between 30 and 40% of patients with epilepsy continue to have seizures that are not adequately controlled by pharmacotherapy (50). Many people who are disabled by epilepsy may be candidates for surgical treatment. Surgery has been performed for epilepsy since the late nineteenth century. During the past few decades, owing to advances in diagnostic procedures, surgery has assumed an increasingly important role in the treatment of chronic epilepsy.

Surgery for epilepsy requires not only a highly trained multidisciplinary team of experienced specialists but also expensive electrophysiological and neuro-imaging equipment. Therefore, epilepsy surgery programmes depend on the economic level of a country. Epilepsy surgery programmes are nonexistent in 98% of African countries, 76% of Asian countries and 58% of European countries.

Surgery for epilepsy is any surgical intervention with the primary goal of bringing relief to patients with intractable epilepsy. The aim of the surgery is to abolish or reduce the frequency of epileptic seizures while keeping the risk for neurosurgical or cognitive side-effects as low as possible.

Surgery for epilepsy requires close collaboration of a multidisciplinary team of highly trained, experienced specialists, including neurologists and paediatric neurologists, neurosurgeons, neurophysiologists, neuropsychologists and neuropsychiatrists as well as neuroradiologists and neuropathologists. A comprehensive evaluation of surgical candidates involves a combination of clinical, electrophysiological, neuro-imaging, neuropsychological, psychiatric and psychosocial evaluations. The electrophysiological evaluations include routine electroencephalography (EEG) and monitoring of seizures with continuous EEG and video recording, not uncommonly with intracranial electrodes such as subdural strips or grids, foramen oval electrodes and, in some cases, depth electrodes (51). Recent advances in neuro-imaging techniques have improved the prospects of finding lesions that might be related to the seizure focus.

### *Outcome of surgical treatment for epilepsy*

The efficacy and safety of surgery for epilepsy had been documented in many observational studies through the years and was recently confirmed in a randomized controlled study of surgical versus pharmacological treatment in poorly controlled temporal lobe epilepsy (52). After one year, 58% of the patients in the surgical group (64% of those operated) but only 8% of those in the medical group were seizure-free. In observational studies, surgical outcome was consistent, did not vary with geographical region (Asia, Australia, Europe, North

America) and was on average identical to the results of the randomized controlled study (53).

Few complications are associated with surgery for epilepsy, and they are related to age (54). Specific epilepsy syndromes that are surgically remediable have been identified. Surgery should therefore not be considered a last resort in such cases but the treatment of choice and should be considered early.

#### *Epilepsy patients who might benefit from surgical treatment*

In the European Region, about 6 million people are considered to have active epilepsy (1); 3.3% of this prevalent population represents almost 200 000 persons who might benefit from surgical treatment of their epilepsy. Data from the United Kingdom indicate that 15 000 cases or 1.5% of the yearly incident cases can be added to this surgical 'pool' (1, 55). These epidemiological estimates point to a significant surgical treatment gap.

#### *Availability of epilepsy surgery*

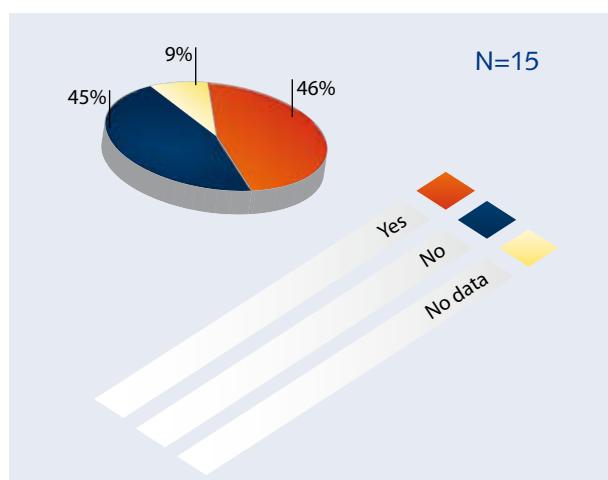
In a survey of the provision of epilepsy care by the Commission on European Affairs of the ILAE (41), all the western European chapters reported that surgery for epilepsy was available in their countries, although to a widely varying extent. The numbers of multidisciplinary epilepsy teams that included surgery were reported to range from 0.06 to 0.68 per 1 million inhabitants. Lack or under-use of surgery was considered to be one of the main problems of epilepsy care across Europe.

The organization of surgical services for epilepsy varies in Western Europe. Several examples have been described. Some countries, such as Germany, have four levels of epilepsy care, the fourth level being represented by a few highly specialized epilepsy centres where surgery is concentrated and where a large number of operations are performed (48). In the United Kingdom, many operations for epilepsy are performed in a few large centres, but some neurosurgeons also perform a smaller number (mean, 13) of operations yearly (55). In Scandinavia, Norway represents one end of the spectrum, with a national epilepsy centre where specialized epilepsy care, including surgery, is concentrated (47).

Sweden has a different system, with no fourth-level epilepsy centre but a network of six regional centres providing specialized epilepsy care including surgery and collaborating in a national epilepsy surgery register. The existence of a national epilepsy surgery register covering all epilepsy surgery procedures in one country has made it possible to determine that referrals for pre-surgical evaluation vary markedly across Sweden (56). A few smaller countries, such as Iceland and Malta, have no epilepsy surgery programmes but depend on international collaboration to send their epilepsy patients abroad for surgical treatment.

Until recently, Denmark also sent some patients abroad for surgery; currently, however, a complete surgical service is being established. Individuals with pharmaco-resistant epilepsy can be identified within a few years of the onset of their epilepsy if adequate antiepileptic medication is taken (50), implying that, after failure of two first-line antiepileptic drugs, patients with medically intractable epilepsy should be referred for evaluation to tertiary referral centres where epileptological expertise will be available to diagnose their epilepsy syndrome and identify suitable candidates for presurgical evaluation.

In comparison with well-developed western countries, central and eastern European countries have fewer diagnostic facilities (video, EEG, MRI), poorer availability of new antiepileptic drugs and few countries have epilepsy surgery programmes.



*Figure 8: Epilepsy surgery programme in selected countries in Europe*

Halasz sent a questionnaire to experts in 15 central and eastern European countries (Armenia, Bulgaria, Czech Republic, Estonia, Georgia, Hungary, Latvia, Lithuania, Macedonia, Poland, Romania, Russian Federation, Serbia, Turkey and Ukraine) and reported the following results (unpublished). The availability of surgery in these countries is illustrated in figure 8. The number of operated patients per year was 10 in Estonia, 23 in Lithuania, 30 in Hungary, 65 in Turkey, 114 in Poland and 150 in the Czech Republic.

#### **Key concerns in epilepsy care**

The ILAE chapters were asked in an open-ended question to identify the main problems in epilepsy care in their countries. Even though there are large regional and national variations in the provision of epilepsy care across Europe, it was striking that the same problem areas were reported. The commonest problems were lack of or under-use of epilepsy surgery; lack of comprehensive care; stigma and social problems; the high cost of (especially the newer) antiepileptic drugs; lack of specialists and of specialized epilepsy care; lack of financing, equipment and resource allocation; insufficient professional education and knowledge about epilepsy and lack of epidemiological data, violation of patients' rights and employment problems. It became clear that people with epilepsy are not a priority and the organization of their health care is inadequate, as patients are not adequately referred from primary to higher levels of care.

In response to the above, efforts are being made to improve the situation in Europe through the following initiatives:

- communication with the European Medicines Agency in order to contribute to the process of and the guidelines for the approval of new antiepileptic drugs
- the development of European guidelines for the treatment of status epilepticus
- harmonising the availability and the indications of antiepileptic drugs across Europe.

### **2.3 Special groups**

Epilepsy affects men and women equally; however, there are both biological and psychological gender

differences with respect to its consequences. Sex-specific hormones affect the seizure threshold, facilitating, inhibiting or modulating the occurrence of epileptic seizures. Because of the close connections between regions of the brain that might generate seizures and regions that control hormonal activity, epilepsy itself can lead to clinically relevant sexual dysfunction, such as infertility or impaired libido. One of the possible side-effects of antiepileptic drugs is an effect on hormones and weight, which can cause medical problems beyond their 'cosmetic' nature. Some of these problems can be dealt with in clinical practice, while others are poorly understood and further research is required. A particular concern is the potential teratogenic effects of antiepileptic drugs used by women of childbearing age. The European Registry of Antiepileptic Drugs during Pregnancy (EURAP), established in 1999, collects information on the pregnancy outcomes of all women treated with antiepileptic drugs.

#### **2.3.1 Men with epilepsy**

Gender-related problems in men with epilepsy are less well studied than those in women. Recent research has demonstrated, however, that men with epilepsy often have various manifestations of sexual disturbance. Furthermore, reproductive function can be impaired due to decreased testosterone levels and reduced sperm quality. These abnormalities might be related to long-term use of antiepileptic drugs, and a number of studies suggest that some drugs have a stronger effect on male hormonal functions than others. Whether these problems can be avoided by using or avoiding specific medications is not yet clear.

#### **2.3.2 Women with epilepsy**

##### **Hormones affect epilepsy**

Sex hormones are known to affect epilepsy. In adolescent girls, the highest risk for developing epilepsy occurs during the year of menarche (57). One-third of women with complex partial seizures describe a relation between seizure occurrence and their menstrual cycle (58), with two seizure peaks around ovulation and menstruation. Almost 50%

of women with epilepsy experience a change in their seizure frequency secondary to menopause, when seizures usually worsen. Experimental data have confirmed the antagonistic effects of the two main female sex hormones on the seizure threshold: estrogens have pro-convulsive properties, while progestogens have an anticonvulsant effect. These interactions are not only interesting with respect to our understanding of hormonal-neuronal network functions but also have clinical implications.

Some women with so called catamenial epilepsy, for example, benefit from adjunctive hormonal treatment.

### Epilepsy affects hormones

Epidemiological studies suggest that women with epilepsy have fewer children than women without epilepsy. One of the many reasons includes a conscious decision not to have a child on the basis of sometimes rational but often irrational worry about epilepsy-related complications in pregnancy and risks for recurrence of epilepsy in the offspring. Some women with epilepsy are involuntarily childless for organic reasons, which might be related to epilepsy and its treatment. Hormonal dysfunction manifesting with menstrual disorders, sometimes associated with the polycystic ovarian syndrome, is more common in women with epilepsy than in the general population. The pathogenesis is not fully understood, but it is likely that epilepsy itself is responsible for disturbances in those central networks that modulate hormonal function. Also, certain antiepileptic drugs can interfere with endocrine systems. Another relevant hormonal dysfunction relates to premature menopause in women with epilepsy, which is likely to be related to higher seizure frequency and may be relevant for women who plan to become pregnant at an older age (59). These problems warrant increased clinical vigilance and further research.

### Epilepsy and pregnancy

One to two out of 200 pregnant women have active epilepsy. In general, there is no reason why women with epilepsy should not become pregnant, but certain risks can be avoided when pregnancies are well planned. A major concern relates to congenital malformations and developmental delay

in the offspring of women with epilepsy who are on antiepileptic medication. While the data on delayed development are still inconclusive, there is unequivocal evidence that the risk for major malformations after intrauterine exposure to antiepileptic drugs is increased by two- to threefold. It is well established that valproate is teratogenic; therefore, if possible, this drug should be avoided in women with childbearing potential. The available data are inconsistent with respect to other drugs, and no useful data are available for most of the new drugs. In Europe, a prospective pregnancy registry was set up in 1999, with more than 8000 pregnancies registered by January 2007. All doctors who look after women with epilepsy are encouraged to participate in this project ([www.eurap.org](http://www.eurap.org)). Although most European countries support EURAP, recruiting rates vary significantly, the highest inclusion rates being about 20% of all pregnancies in the Scandinavian countries and Italy.

Several national studies have shown that women with epilepsy are poorly informed about pregnancy-related issues. As many complications during pregnancy can be avoided, it is recommended that women receive appropriate information as soon as epilepsy has been diagnosed. An important prophylactic measure for persons with major malformations and particularly neural tube defects is folic acid supplementation. In Germany, however, only 50% of women registered in EURAP were taking folic acid prior to conception.

## ■ 2.3.3 Children and adolescents

Epidemiological studies have shown that epilepsy is more frequent in childhood than in adolescence (60). The epilepsy syndromes in childhood and adolescence fall into several groups and subgroups, for example with and without photosensitivity. Epilepsy syndromes that appear in childhood can remit, change character or persist in adolescence. Other syndromes have onset in adolescence. The epilepsies in childhood that remit in adolescence are benign myoclonic epilepsy in infancy, childhood absence epilepsy (pure), early onset occipital epilepsy (Panayiotopoulos syndrome), benign epilepsy with centrotemporal spikes, Landau-

Kleffner syndrome, epilepsy with continuous spike and wave during slow sleep and some generalized and focal epilepsies.

Epilepsy in childhood that continues or may continue into adolescence includes childhood absence epilepsy with negative prognostic factors, epilepsy with myoclonic absences (Tassinary syndrome), eyelid myoclonia and absences (Jeavons syndrome), juvenile myoclonic epilepsy with early onset, juvenile absence epilepsy with early onset, facial myoclonia with absences, occipital epilepsy (Gastaut type), generalized tonic-clonic seizures on awakening, epilepsies associated with mental handicap and severe forms of epilepsy such as Lennox-Gastaut and severe myoclonic epilepsy in infancy.

Epilepsies with onset in adolescence include juvenile absence epilepsy, juvenile myoclonic epilepsy, generalized tonic-clonic seizures on awakening, photosensitive epilepsy, mesial temporal lobe epilepsy, progressive myoclonic epilepsy and other partial or post-traumatic epilepsies.

Good medical care is therefore insufficient to prevent associated problems. Young people with epilepsy experience a real struggle in negotiating educational systems and work opportunities. The barriers that keep them back must be identified, in consultation with the medical profession at an early stage. Each family has its own emotional response to seizures and epilepsy, and their doctor must listen to their feelings and experiences and provide suitable information. The quality of communication will depend on the degree of confidence.

### **Children with epilepsy**

Overprotection and pampering of children with epilepsy leads to behavioural problems, low self-esteem, poor self-image, long-lasting dependency and negative personality characteristics. The education of children with epilepsy is hampered to varying degrees, as the course and evolution of epilepsy may affect intellectual capacity, attention and memory. The social integration of young persons with epilepsy depends on their reactions to their condition and to their family and society. Parental disharmony and family dysfunction due

to depression may lead to educational and social failure. Poor seizure control reduces the capacity to participate in social activities, resulting in greater isolation.

In children, most of the syndromes that remit in adolescence leave no long-term consequences. These children will be able to stop medication and might gradually forget all the bad memories of childhood. Their parents could gradually impose fewer restrictions, and the child will be free to develop an independent personality closer to that of other children of the same age.

### **Adolescents with epilepsy**

It is common for adolescents to have independent minds, which reflects in their relationships with family and society. Their ideas are influenced by their peers and often in opposition to those of their parents. The adolescent way of life often includes going out late with friends, travelling etc, resulting in lack of sleep, which can provoke certain seizures. Parents therefore often tend to impose restrictions, which are multiple in the case of epilepsy.

Adolescents with epilepsy might object as the medication becomes a subjective burden and obstructs their activities, and they might try to stop taking it. Adolescents often do not report minor seizures for fear of having to increase their medication. They make every effort not to be rejected by their peers but can lack the strength to stand up for themselves, and attempt to conform.

Depression, suicide and sexual abuse can sometimes be the consequences of perceived failure (61, 62). In particular, seizures can influence the behaviour and life-style of adolescents, expressed as poor performance at school, fewer outings, weight gain or loss, drinking, smoking or substance abuse.

Anorexia can also be a problem, and certain antiepileptic drugs can aggravate the situation.

Adolescent girls with epilepsy are sensitive to the cosmetic adverse effects of some antiepileptic drugs. Pregnancy can be a risk due to interactions of anti-epileptic medication with the contraceptive pill.

Adolescents want to obtain a driving license (63, 64) and seek job opportunities. They often discuss their future, marriage, the risk of having children and the hereditary risks of epilepsy.

### 2.3.4 The elderly

Until recently, the common perception has been that seizures and epilepsies occur most often in childhood and adolescence and rarely in older persons.

Today, however, epilepsy is the third most common neurological disorder in old age, after dementia and stroke, mainly because of steadily increasing life expectancy and an increased likelihood of surviving concurrent medical conditions that can lead to seizures or epilepsy.

The underlying cause of seizure activity can be identified in most older patients (13, 74). Causes of seizures in patients who had a first seizure after the age of 60 were identified in a 5-year study (table 3), (75).

stroke	32%
brain tumour	14%
no identifiable cause	25%
other	29%

Table 3: Causes of first seizure after age 60

Seizures can recur immediately after a stroke or not for several years (76). Advanced Alzheimer disease has been identified as a risk factor for new-onset generalized tonic-clonic seizures in older adults (77, 71) and is associated with a 10% prevalence of seizures, particularly late in the illness. Increased prevalences of seizures have also been documented with other types of dementia. A study of 342 patients with status epilepticus who had their first seizure after 60 years of age showed that cerebrovascular disease was the leading cause, followed by head trauma (78).

The clinical manifestations of epilepsy in the elderly are different from those in younger adults and children. The most common seizure types in the elderly are complex partial seizures, which may be shorter and less impressive than those seen in younger patients. In contrast, the elderly often have

more severe, prolonged post-ictal symptoms. Post-ictal confusion with disorientation, hyperactivity, wandering and incontinence can persist for up to one week. Nonconvulsive seizures and nonconvulsive status epilepticus are quite common in the elderly and can cause sudden changes in behaviour and cognition.

As seizures occur more frequently among people living alone than in the younger generation, there is often no reliable personal history or observations by third persons. The reports of an afflicted patient are often less reliable owing to forgetfulness or accompanying neurological and psychiatric diseases. It is thus not surprising that, in a French study, a correct admission diagnosis was made for only every second patient and that in many undefined crises a state of confusion or a transient ischaemic attack was suspected (79).

An adult with a first seizure with no clearly recognizable cause should always be given an adequate diagnostic examination to exclude a symptomatic cause. The examination should comprise at least computed tomography with contrast medium, although magnetic resonance imaging is preferable (80).

The Veterans Affairs Cooperative Study on the effects of age on epilepsy and its treatment indicated that older adults are more likely than younger adults to be responsive to antiepileptic therapy, but they are also more likely to experience side-effects at lower serum drug concentrations (81). Thus, patients should be monitored closely for adverse effects, drug interactions, poor seizure control and toxicity (82). Once the decision to treat has been made, the next step is to determine whether a standard (older) antiepileptic drug or one of the newer agents is to be used. The newer drugs have been shown to be significantly better tolerated (83, 84).

A review of published studies of antiepileptic drug-prescribing patterns suggests that current clinical recommendations have been adopted, at best, slowly (85). Research is needed targeting barriers to more appropriate prescribing in order to determine appropriate strategies for changing antiepileptic drug prescribing practices for the elderly.

Individualized general management, including reassurance and education for patients and carers, is important. A multidisciplinary approach that includes care for both somatic and psychiatric co-morbidity is essential.

A first generalized tonic-clonic seizure with a fall or another seizure type with loss of control might be a watershed event in an older person's life, with a decline in functional independence and confidence ('fear of further fits' (86). The public, general practitioners and the staff of nursing homes should be made aware of the related problems.

In addition to the patient - with his or her consent - family members and all the professional carers involved should be informed. Increased attention should be paid to safer surroundings, intake of prescribed medication or compilation of a seizure diary.

## ■ 2.4 Education

There is a complex interplay between learning ability and epilepsy, which can result in a greater risk of children with epilepsy being misunderstood and excluded and of being denied equal opportunities for learning and development of their full potential (65). Attitudes both at home and at school can interfere with a child's academic progress, and with their self image. Time at school and learning activities might be missed unnecessarily, reducing the opportunities for academic and social development. Learning and behavioural problems are often called 'hidden dysfunctions in childhood epilepsy' (66).

### Types of learning difficulties

A learning disorder is a significant disturbance in academic achievement or daily living activities that require reading, mathematics or writing. There are several types of learning difficulties, and it is important to differentiate underachievement from intelligence quotient (IQ) in areas such as reading and arithmetic. Learning disability (mental retardation) has been defined as a reduced (< 70) IQ and significant limitations in adaptive and social functioning. Vigilance is the ability to remain

in contact with the outside world; attention is the ability to select and focus information; while memory is the ability to memorize data (67). Depending on the state of the individual at the time, the epilepsy itself (inter- or post-ictal), effect of treatment, mood disorders, low self-esteem or reduced learning opportunities are therefore potentially treatable and reversible. While certain antiepileptic drugs reduce the attention span or affect memory, others can improve learning by reducing the number of EEG discharges or seizure frequency (68).

### Frequency of learning difficulties in epilepsy

Factors such as underlying brain lesions, epilepsy characteristics, attention disorders, sub-clinical epileptic activity, drug side-effects, cognitive functioning and secondary psychosocial problems can alter a child's learning potential. Most children with epilepsy function satisfactorily with proper anticonvulsant medication; however, as a group, they tend to run a greater risk for learning problems and to have schooling difficulties. It has been estimated that, excluding children with mental disability, 25-50% of children with epilepsy have some degree of educational difficulty. The effect of medication on cognitive function should also not be ignored (69).

Several studies in Europe have found a range of learning difficulties in children with epilepsy. In the European Epilepsy Services inventory of the needs and resources available for the provision of basic epilepsy care across Europe (41), the various ILAE chapters reported wide differences in the provision of education and care in their countries.

A landmark study carried out in Finland (70) showed that, despite normal intelligence, students with epilepsy tended to be one year behind the expected reading level; have variations of over 10 points in IQ scores over four years; tend to repeat grades more often; drop out of school at higher rates during adolescence; have deficits in language, visual-spatial function, problem-solving and adaptive behaviour and have dramatically reduced educational and professional attainment, employment status and likelihood of marriage and future childbearing.

In the Netherlands, having epilepsy was found to have a markedly negative impact on education and achievement in later life (68). Despite worse psychosocial outcomes than the general Dutch population, patients with epilepsy coped well with their condition, regardless of their handicaps.

A prevalence study in Malta (67) showed that 82% of children with epilepsy were attending mainstream schools, while the other 18% attended special schools. Among those attending mainstream schools, 53% were reviewed by educational psychological services because of learning difficulties, including difficulties in learning to read and write, alterations in memory processing, speed of information processing and changes in sustained and focused attention.

### Solutions

Appropriate interventions and a positive approach to the problems can reduce the risk of pursuing a downhill course of frustration, failure and diminishing self-esteem for all concerned. Early integration into a group is of considerable importance in preventing feelings of inferiority and fear of what is not the norm among children in a peer group. This can be addressed by means of stories (71), and any bullying can be tackled by involving the child in social activities such as outings. Uninformed teachers and peers see children with epilepsy as different and may be unable to meet their needs, thus reducing expectations and opportunities for their learning and social development. Teachers and schools must be informed of a child's condition and about the exact type of epilepsy, primarily the seizure type and treatment. Unrecognized seizures, such as absence seizures, can disrupt learning due to inattention, poor memory, psychomotor slowing and deficits in executive functioning. Mainstreaming of children with epilepsy can lead to greater anxiety among school staff and can lead to social exclusion (62). Information for teachers and facilitators should be included in their courses by audiovisual aids or at annual conferences and in-service training courses for teachers.

A study in the United Kingdom in seven local

secondary schools (72) showed that schools rely heavily on obtaining medical information from non-medical sources, and none of the schools had created individual health care plans for children with epilepsy, while six of seven schools reported appropriate provision for such children during swimming activities. The commonest restriction was related to computer use. Nine schools stated a need for more training of staff members with regard to seizure management.

### Interdisciplinary action

Education for people with epilepsy is a complex issue and is a life-long process. Psychological and social support are needed, as the external locus of control in epilepsy is often associated with depression, poor effort in school, the possibility of isolation of adolescents, anxiety about health and social standing and poor self-esteem. The children themselves should experience positive interdisciplinary approaches to their condition by their parents, educators and peers. Concrete comprehensive action is needed in Europe to improve the educational system for such children, so that each child's needs can be met satisfactorily (73).

## ■ 2.5 Economic Issues

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Health-care economics is a relatively recent specialization. Even more recent is the preoccupation with the economic aspects of epilepsy. This theme was first discussed in 1993 at the 20th International Epilepsy Congress, Oslo, Norway. The principal objective was to apply existing, proven instruments of health-care economics to the field of epilepsy and its treatment (87-89).

Over the past 15 years, there has been a clear shift in the direction of scientific studies in the field of epilepsy. While, firstly, the costs of epilepsy were studied and cost-benefit studies then carried out, and in a further step, structural questions about the treatment of epilepsy were dealt with; more recently, a comparative study of different health-care systems and their effects on epilepsy care has been carried out.

In the 1990s, studies concentrated mainly on the

costs of epilepsy, taking into account both direct and indirect costs. Direct costs include payments for medical treatment and care (e.g. doctors, antiepileptic drugs and therapies) and for non-medical measures in the educational, occupational and social fields. For the indirect costs, the fact that persons with epilepsy are more often unemployed or underemployed than other people is also taken into account. Non-healthcare items include transportation costs, informal nursing, and social services provided in institutions or at home, and unpaid care or services provided by patients' relatives. Very few studies have attempted to account for the cost of non-healthcare services in addition to healthcare and comparable estimates of the indirect cost of epilepsy, which accounts for the majority (perhaps 70-85%) of the total cost of epilepsy (90).

In the second phase, economic studies addressed selected individual aspects of the treatment of epilepsy, such as antiepileptic drugs or surgery. This gave rise to various cost-effectiveness studies, of the economy of individual therapeutic measures, to determine the economic superiority of certain treatments. Especially in the pharmaceutical industry, which at that time was introducing several new antiepileptic drugs onto the market, there was concrete interest in relating the relatively high prices of the new drugs to a corresponding economic advantage. At the same time, several studies into the economic implications of epilepsy surgery were reported, in which the principal objective was to show that the otherwise relatively high costs of life-long treatment could be avoided by a relatively costly operation.

In the second half of the 1990s, the problems of financing the general health-care sector became more acute in all the countries of Western Europe (figure 9). In these disputes, it was those who were able to prove the cost-effectiveness of comprehensive packets who in fact received the necessary funds. In this third phase, health-care economy started to look into structural questions relating to the whole field of epilepsy care. In the field itself, there was now greater interest in the cost-effectiveness of structural programmes (e.g.

the advantages of decentralized epilepsy outpatient clinics, integral treatment models for an entire region or vertical integration of services).

Since the turn of the century, yet another theme has become the centre of interest, which is the health-care policy aspects of epilepsy care, especially as the further long-term development of epilepsy care depends on health-care policy and the financial situation. For this reason, in 2001, the ILAE set up a Commission on Health Care Policy, which was given the task of studying different health-care systems and analysing the effects on people with epilepsy and on treatment of the condition. The express aim was to compare the quantity and quality of epilepsy care in different countries in which enquiries had been carried out recently (41). Also over the past few years, theoretical instruments for making comparisons and for evaluating different health-care systems have been elaborated by the World Health Organization.

In consultation with WHO, the ILAE Commission on Health Care Policy (2001-2005) examined the applicability and usefulness of various measures for monitoring epilepsy healthcare services and systems across countries. The aim was to provide planners and policy makers with tools to analyze the impact of healthcare services and systems and evaluate efforts to improve performance. A systematic literature review was conducted and experts were consulted. Furthermore a pilot study was conducted to determine the feasibility and applicability of using new measures to assess epilepsy care developed by WHO including Disability Adjusted Life Years (DALY's), responsiveness and financial fairness. It was concluded that the epilepsy field should consider adopting the WHO measures in country assessments of epilepsy burden and healthcare performance whenever data permit (90).

### **Consequences for epilepsy care**

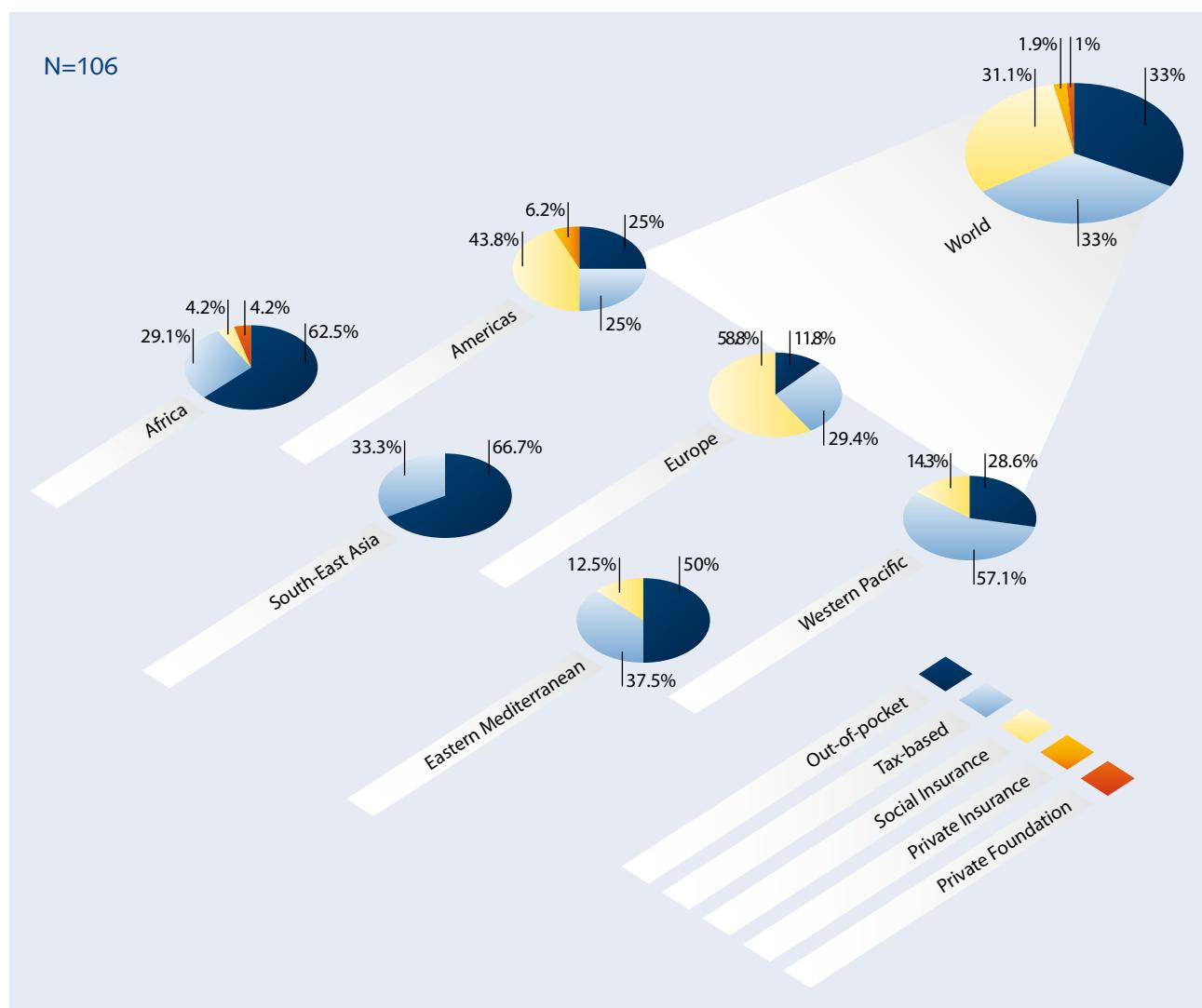
Knowing the cost of epilepsy increases awareness of its burden on individuals and society, and the potential benefits of prevention and treatment (90). Economic studies of epilepsy have shown that the socioeconomic consequences of this disease are often underestimated. In particular, the

indirect costs of epilepsy, due to unemployment, underemployment or premature death, are higher than generally assumed. For those involved, and for the economy, it is the high level of unemployment among people with epilepsy that is most important. Different studies have shown that, in Europe, unemployment is twice to three times higher among people with epilepsy than in the general population (91).

Cost comparisons in several countries have shown that the average costs of a person with epilepsy vary significantly. It is difficult to determine whether the differences are due to different unit costs or to

different use of health-care resources. Nevertheless, prices for antiepileptic drugs and other treatments vary considerably between European countries (92).

Studies indicate a substantial variation with respect to the direct cost of epilepsy for both prevalence and incidence cases, but a fairly consistent pattern with respect to determinants of variation in direct cost (90). A prevalence based UK study determined the average annual cost in 1992 through 1993 for a general sample of 1.000 cases from a UK health region. They found that people with epilepsy having one or more seizures in the last year had seven times higher annual epilepsy-related healthcare cost than



*Figure 9: Primary method of financing epilepsy care in WHO regions and the world based on best estimates of respondents (Atlas: Epilepsy Care in the World 2005)*

that of persons who were seizure free (US\$ 1.763,- vs. US\$ 243,-) (89). Incidence-based studies also have variable findings with respect to cost levels but indicate similar patterns of high initial costs at onset for most patients, followed by much lower costs in subsequent years (90). An incidence-based study in France determined the direct healthcare cost of 1942 patients with newly diagnosed seizures for two years in France. The mean annual direct cost per patient was estimated to be US\$ 2.432,- and US\$ 640,- for the first and second years of follow-up respectively (93).

A wider range of therapeutic possibilities is available to people with epilepsy in Europe than elsewhere in the world. Nevertheless, considerable differences exist in regard to the accessibility of and the degree of recourse to epilepsy-specific services in Europe and also in individual countries. It is known that the provision of medical services depends more on the available financial resources than on the need. For example, the number of hospital beds for epilepsy care is five times more in Europe than in America (figure 10).

In high income countries in the region, the treatment and care of epilepsy is faced with the dilemma of increasing demands on its services on the one hand and stagnating financial resources on the other. At the same time, countries are taking steps to limit the growth of health-care costs. The procedure and the instruments used to curb costs differ among countries. Common to them all, however, is the increasing trend for financing based on services provided, rather than direct financing of the providers of the services, as has been the case up until now. This development will not be without effects on epilepsy care. From the economic point of view, it will be important to be able to justify adequate expenditure for the treatment of people with epilepsy to those providing the resources, so that the services can be financed sufficiently.

During the period of profound economic and political transition, several low income countries of the region saw a deterioration of the care of epilepsy that had existed under the previous comprehensively socialized health system, even though the financial

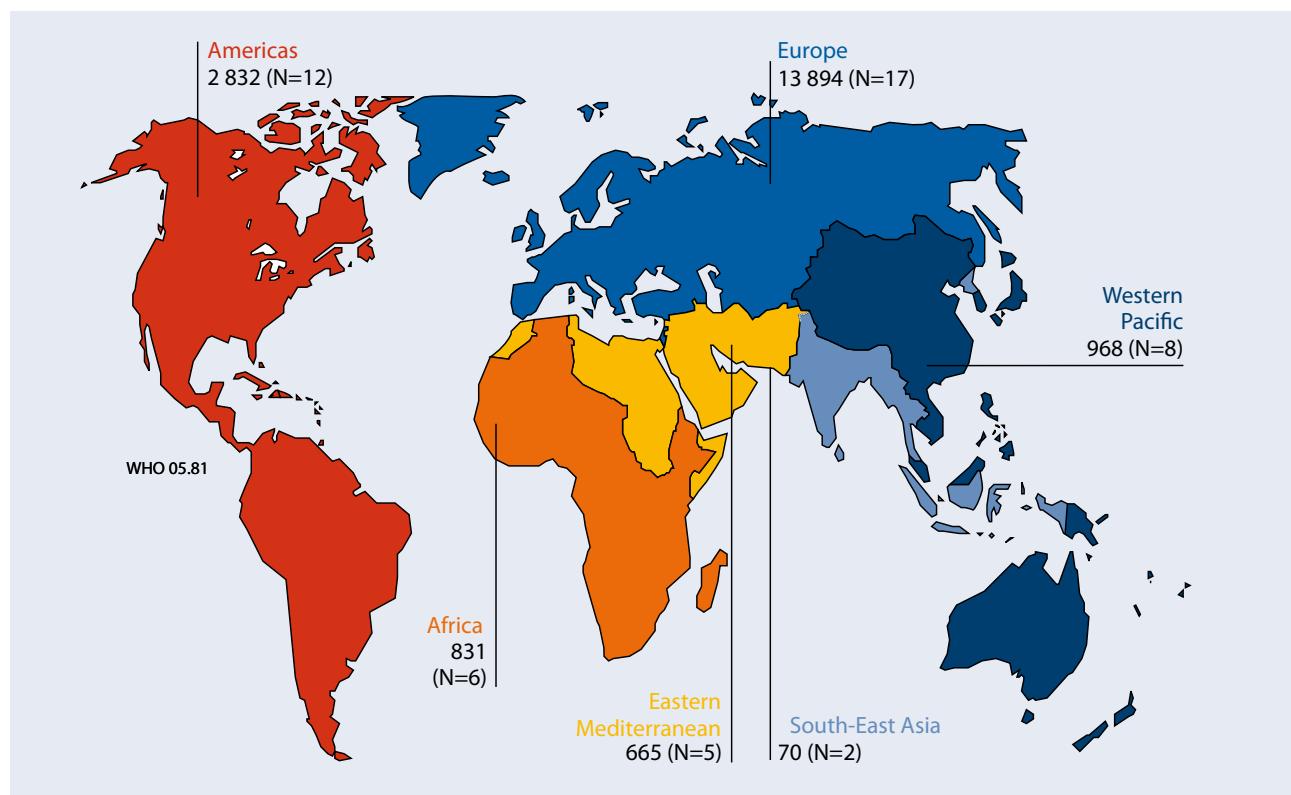


Figure 10: Number of beds for epilepsy care in WHO regions (Atlas: Epilepsy Care in the World 2005)

resources were modest and quality of care provisions limited. The fragmentation of the existing networks of care into sectors that do not always cooperate as they used to, resulted in lack of support for community and district health centres offering multidisciplinary secondary medical care, including child health, gynaecology, dental care, mental health and occupational medicine in addition to general medicine. The introduction of private medicine, with insufficient attempts to preserve the functional advantages of the previous networks, could in particular compromise care for patients with chronic conditions, those with co-morbid conditions and the socially less advantaged. For patients with epilepsy, especially those with a severe disorder or a condition associated with psychological and social co-morbidity, these factors might affect their quality of life, in addition to the general social destabilization caused by political and economic change.

## ■ 2.6 Social and cultural issues

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### 2.6.1 Social issues

Any health professional working with persons with epilepsy is aware of social problems that make their patients' lives a predicament, an existence burdened by more adverse social factors than those of the disease itself. This is less obvious to decision-makers in social welfare, health politics, education and the media and even to medical colleagues, including neurologists, working in other domains. Nevertheless, their decisions about society's social practices have a crucial influence, comparable to that brought about by modern pharmacotherapy, on the quality of life of persons with epilepsy.

Epidemiological studies have shown that the seizures of up to 70% of people with epilepsy are well controlled by antiepileptic medication, and there is evidence that epilepsy does not profoundly diminish the quality of the everyday lives of this group. The outlook may be less optimistic for the remaining 30%, whose seizures are chronic and intractable (94). Earlier studies highlighted a number of areas of particular concern to people with epilepsy (95), who tend to have poorer self-esteem and higher levels of anxiety and depression than people without epilepsy (96). They are more likely to be under- or

unemployed and to have lower rates of marriage and greater social isolation (97). Some people with epilepsy feel stigmatized by their condition.

At its most extreme, epilepsy is associated with increased mortality. While increased mortality may in some cases be due to the underlying causes of epilepsy, the rates of death from accidents and trauma are also higher. For example, people with seizures are twice as likely to die from drowning as people without them. There is some evidence that death from suicide is more common among people with epilepsy. The risk of non-fatal accidents, including fractures and burns, is also higher for people with epilepsy than others. Less dramatically, people with epilepsy have to contend with the side-effects of antiepileptic medications, which might be both cognitive and physical. In a recent European study, the reported levels of side-effects from medication were high, those most commonly reported being tiredness, memory problems and difficulty in concentrating. A significant number of respondents reported changing their medication because of side-effects or poor control (98).

### Psychological function

In studies of the psychiatric and psychological outcomes of epilepsy, the prevalence of psychiatric morbidity has been found to be high, with about one-third of people with epilepsy affected. Anxiety and depression are the two most common manifestations of psychopathology reported, anxiety being the problem most commonly elicited from patients themselves (99). It has been suggested that protracted anxiety is the precursor of depression, and the two problems commonly co-exist in epilepsy. Depression was the commonest reason for admission to hospital for psychiatric care in a study of people with epilepsy. In the community study cited above (99), 9% of subjects were classified as depressed and a further 15% were 'borderline'. As for anxiety, the percentage of subjects thus classified rose with seizure frequency, from 4% of those currently seizure-free to 21% of those with seizures more often than once a month on average. Depression can be self-reinforcing, and its associated sequelae, such as loss of confidence and reduced self-esteem, can be more disabling and longer-

lasting than the depression itself.

Another common psychological problem for people with epilepsy is a poor sense of mastery. Potential sources of reduced self-esteem are parental overprotection and rejection, educational and occupational underachievement and perceived stigma and discrimination (95). Perhaps because of the unpredictable nature of seizures, people with epilepsy tend to have a poorer sense of mastery than healthy people; a number of authors have shown that sense of mastery is significantly related to other psychological variables. Similarly, it has been shown that a poor sense of mastery in adults with epilepsy was significantly and positively related to anxiety, depression and a number of somatic symptoms: the more the respondents believed that their health was controlled by forces external to them, the more anxious, depressed and ill they felt. There is also a significant body of evidence detailing the stigma associated with this condition (100, 101).

### Social functioning

Social withdrawal and isolation are commonly reported among people with epilepsy. Such isolation is frequently the product of anxiety about the possibly hostile reactions of others if a seizure should occur in a public place. Previous research also indicates that fear for their physical safety keeps many people isolated: more than one-fifth of the people in one study said they were afraid to go out because of the possibility of seizures occurring that might lead to accidents; their most common coping strategy was therefore to stay at home. It has been suggested (100) that such fears lead to self-denial of opportunities, which can in turn result in a whole host of problems with personal relationships.

Problems in personal relationships are reflected in the lower rates of marriage and fertility among people with epilepsy than in the general population. A comparison of epilepsy and non-epilepsy samples in the United Kingdom showed that 71% of the non-epilepsy group but only 42% of the epilepsy group were married (95).

There is some evidence that social withdrawal and isolation are also the product of parental reactions to a diagnosis of epilepsy, which typically involve

over-protection. This can lead parents to limit their children's activities, rendering them more socially inept. Children with epilepsy are more dependent on and attached to their parents. They also adopt a more passive role in family interactions and are less involved in family decision-making. Both under- and unemployment are more common in people with epilepsy. Previous research suggested that up to one-half of all people with epilepsy living in the United Kingdom experienced problems of employment. Complementary research has shown that people with epilepsy had significant difficulties in obtaining work, perhaps in part due to educational underachievement.

In the European study (98), high percentages of respondents reported that epilepsy substantially affected their plans and ambitions for the future, their feelings about themselves and their social lives; conversely, high percentages considered that their relationships with 'significant others' were unaffected. Over one-third of respondents considered that epilepsy affected their ability to work, the nature of the work they could do and their standard of living, but substantial proportions felt that aspects of employment and their standard of living were unaffected. There were significant variations according to country (table 4). Information from a number of lower and upper middle income countries reveals similar problems. In the Nakhchivan area of Azerbaijan, there was much community prejudice against people suffering from epilepsy. Parents and young women preferred to keep the fact of seizures secret, because disclosure affected marriage rates or resulted in divorce (S. Magalov, personal communication, 2004). In Estonia, 55.4% considered that they had been treated unfairly at work or when trying to get a job. Stigmatization due to their condition was felt by 51% of respondents, and 14% felt this strongly. Nevertheless, the level of employment among people with epilepsy was not lower than that in the general population (102).

The marriage rate among persons with epilepsy in Estonia was about half that in the general population, and they had fewer chances of adequate employment. In studies of the quality of life of

adults with epilepsy, the frequency of seizures was the most important factor (40).

A survey was performed amongst medical professionals in the middle income countries in the Region and responses were received from Albania, Armenia, Croatia, Hungary, Macedonia, Serbia (including the situation in Montenegro) and Slovenia.

The idea that the quality of life of persons with epilepsy is strongly associated with social factors has been reasonably well accepted in professional circles of six of the countries. In the other countries, most doctors appeared to accept that the social issues of persons with epilepsy are part of their professional commitment. The answers confirm the continuous interest and endeavours of health professionals in this part of Europe in the social issues of epilepsy.

The key role in dealing with social issues was unevenly distributed among professionals in health services and the social authorities. The former have more epilepsy-specific knowledge, while the latter have more knowledge about social fields and statutory powers of decision. The contribution of social workers, i.e. professionals allied to medicine, appeared to be low in most countries. Training of social workers about epilepsy was poorly developed in nearly all the countries. The question of the best blend of medical and social services and of the best distribution between the health system and social authorities remains to be discussed. Regarding employment, cooperation between neurologists and neuropsychologists, occupational physicians and social workers is of primary importance. Staffing and

teaching practical skills in these specialties might be one of the most important actions for improving the quality of life of persons with epilepsy.

It is clear that a person can be handicapped by epilepsy, even if not disabled by it, and that, because of stigma and discrimination, the handicap can persist even if the levels of impairment and disability improve. The evidence clearly demonstrates that epilepsy and its treatment can and does have a significant impact on individual physical, social and psychological well-being and that this is independent of the country of origin. The differences between countries have been explored previously and a number of explanations offered. In countries with no structured national tertiary epilepsy centre or multidisciplinary team, it would be difficult to introduce standard professional concepts in the medical, social or psychological domain in a planned, coordinated manner. Even when a tertiary centre exists, it does not necessarily also cover social issues; on the contrary, the social dimension is dealt with at community or district level, where epileptological expertise is not present. It is clear from published findings that programmes aimed at improving patients' ability to manage their condition should address the impact at each level. Improving the quality of life of people with epilepsy requires initiatives at local, national and international levels.

## 2.6.2 Cultural aspects

Having epilepsy is a complex mix of physiological phenomena and related psychosocial processes that are shaped and acquire meaning within specific cultural contexts. Cultural factors play a role in shaping people's health behaviour and can therefore influence rates of disease as well as people's ability

Felt that epilepsy affected a lot or some	Percent responding							
	France	Germany	Italy	Netherlands	Spain	Sweden	Switzerland	United Kingdom
Relationship with family	33	21	31	17	24	40	16	25
Social life	49	43	40	32	34	44	34	44
Ability to work	47	38	36	31	36	46	37	34
Health overall	38	30	36	27	28	45	24	34
Relationship with friends	36	23	36	18	21	37	19	26
Feelings about self	47	37	36	32	40	45	28	44
Plans for the future	56	48	52	37	40	51	32	50
Standard of living	41	35	44	30	32	46	28	34

Table 4: Responses regarding perceived impact of epilepsy, by country From Baker et al. (1997)

to cope with it (103, 104). In the context of epilepsy, the issue of culture is usually raised in relation to stigmatization, but cultural factors also influence the epidemiology of epilepsy, health-care seeking patterns and the treatment gap.

From the standpoint of health care, cultural factors are often represented as obstacles to adequate delivery of care and management, for instance when people's ideas cause a delay in seeking treatment or lead to stigmatization and isolation. Cultural factors might encourage adequate management of epilepsy, for instance when religious beliefs support help-seeking or when an ideology of human rights or widely shared social norms protect people with illness and disabilities from social exclusion and discrimination.

In considering the role of cultural factors in a European context, one might ask whether there is a specific European cultural approach to epilepsy or a shared approach that can be distinguished from, for example, an African or American approach. One might also ask to what extent European cultures differ with regard to epilepsy and epilepsy care and to what extent cultural factors explain European cross-cultural differences in living with epilepsy or the management of epilepsy. However, there are few comparative data on epilepsy and culture in the European context, and the following discussion does not so much reflect evidence as it tries to identify gaps in knowledge and research needs.

### Cultural factors and choice of therapy

The extent to which people with epilepsy have access to appropriate treatment differs widely in different areas of the world. A recent survey showed that there are large differences in epilepsy care provision across countries in Europe and between regions within countries on the rural-urban and North-South dimensions. Problem areas are more pronounced in Eastern Europe but are reported throughout the region (41). Migrants in Europe generally have poorer access to health services than the rest of the population (105), but no reliable comparative data are available on their use of epilepsy services.

Little is known from a European perspective about the types of alternative epilepsy treatments available to European populations or the extent to which people with epilepsy make use of them. In Turkey and among migrant populations, religious or traditional healers are consulted as well as or instead of biomedical physicians (106). In a small survey in a specialized epilepsy centre in the Netherlands in 1985, 12% of Dutch patients had visited alternative healers (107). There is no reason to assume that this percentage has lessened overtime or that this type of medical pluralism is specific to the Netherlands.

People's health-seeking activities can affect whether they are adequately treated, and their health beliefs and practices will affect those activities. Recognition of symptoms, ideas about the causes of epilepsy and the efficacy of treatment options, stigmatization, acceptance of chronic illness, and the meaning of and attitudes to medication all play a role in people's therapy choices and may result in delayed or no consultation or non-adherence to medical regimes (108). Patient non-compliance with medication and rules for daily living have received attention from physicians and behavioural professionals in relation to all chronic illness; however, health choices that might seem irrational to doctors might have rational reasoning behind them from the patient's point of view and in the context of the patient's daily life (109, 110). A large study of epilepsy support groups in ten European countries showed that people with epilepsy are reasonably well informed but that there are significant cross-cultural differences in the level of medical knowledge about epilepsy, especially concerning medication and causes (111). Obviously, health beliefs affect the type of knowledge about epilepsy that people can, want and will embrace. No clear insight is available, however, on the relative impact of health system factors, level of knowledge and specific health beliefs on the rate of seizure control, delayed consultation, self-management practices and non-adherence in specific cultural contexts, in different countries and regions and among specific population groups.

### Culture, stigmatization and psychosocial impact of epilepsy

The issue of social stigmatization of persons with

epilepsy in Europe is discussed elsewhere in this report. A comparative study of this topic from a European perspective (112) raised pertinent questions about the relative causal role of cultural factors in the complex social processes that lead to perceived and enacted stigmatization of people with epilepsy. There are few qualitative studies that might clarify the sometimes contradictory findings from surveys on the complicated workings of stigma in the daily lives of these people, their self-identity and life trajectories, and they are seldom comparable.

A study on Dutch social images of epilepsy and the self-identity of people with epilepsy (113) showed how classic ambivalent stereotypes are re-created and given new cultural meaning through the interaction of patients with their family members as well as with health professionals in modern health-care settings.

Elsewhere in this report, psychosocial aspects of having epilepsy are discussed (p.32-33). Here, we can ask how cultural factors interact with the impact of epilepsy on the lives of sufferers. More is known about developing countries than Europe, although all the data are patchy and difficult to compare. A comparative European study on cross-cultural differences in the quality of life of people with epilepsy (114) showed that differences among countries remained highly significant even after control for other sociodemographic and clinical variables. More research is required into the reasons behind cross-cultural variation in quality of life and the way in which different factors interact.

Two of the hypotheses identified for further research specifically address cultural issues, namely differences in social attitudes and contrasting life expectations and outlooks. Smaller studies underscore this conclusion, for instance in relation to cultural and historical differences in the weighting of problems, that is, the extent to which similar problems, such as fear of seizures or social isolation, are experienced differently as problems by different populations or by the same population at different periods (115), or when issues are identified within one country as affecting quality of life and are known to be shaped by cultural factors, such as

could be argued for self-efficacy (sense of mastery) and social support (116).

From a European perspective, evidence on the role of cultural factors in how epilepsy is experienced and managed is also scarce and patchy, especially as concerns therapy choices. Data on health beliefs and rules for living with epilepsy are missing for many countries and regions of Europe and for demographic and cultural groups that might face particular problems in their cultural approach to epilepsy, for instance migrants and refugees. The comparative data available suggest great diversity and also a core role of cultural factors in explanations of differences, especially in the psychosocial impact and stigmatization of epilepsy, albeit in interaction with many other factors. A recommendation for more research seems apt. The gaps in knowledge are vast, however, and will require clever combinations of quantitative and qualitative research designs aimed at target areas or populations in which the problems are most apparent or expected. It is proposed here that rural areas, Eastern Europe and migrant populations deserve our first attention.

### **Stigmatization**

Both historically and cross-culturally, and with only rare exceptions, epilepsy has been represented as a stigma and, for many people with epilepsy worldwide, this is the continuing social reality. Despite a rapidly changing clinical approach for persons living in the developed world, it has been argued that, even in this context, the legacy of the old myths about epilepsy lingers on, with the result that people with epilepsy are still subject to negative attitudes. The issue of stigmatization remains 'real and serious' (117). In this brief account, the situation for people with epilepsy living in European countries is described and suggestions are made about how the issue can be tackled in the European context. Given that the visibility of epilepsy is linked to the frequency of seizures (its outward manifestation), one might expect the degree of stigma associated with it to be less in developed countries, where accessible treatment allows a good level of seizure control, than in developing countries, where the treatment gap is large and seizure control is consequently less easily achieved. The assumption

that good control and low visibility of seizures liberate persons with epilepsy from the experience of stigma is not, however, necessarily supported by the available evidence. Rather, what research suggests is that the stigma experience of these worlds is different, with 'felt' stigma a much more pervasive element in developed cultures, including those of northern Europe, and 'enacted' stigma predominating in the developing world (100) (table 5).

Felt stigma	Shame associated with being epileptic and fear of encountering stigma
Enacted stigma	Actual episodes of discrimination against people with epilepsy solely because they have epilepsy

Table 5: Felt and enacted stigma

In research conducted in Europe and the USA, stigma was positively associated with impaired self-esteem, self-efficacy and sense of mastery, perceived helplessness, increased rates of anxiety and depression, increased somatic symptomatology and reduced life satisfaction (118, 101, 98, 119). In a European-wide study of people with epilepsy, the authors found that overall quality of life was poorer for persons reporting higher levels of stigma (figure 11). Suurmeijer, Reuvekamp and Aldenkamp (120) studied quality of life in the Netherlands

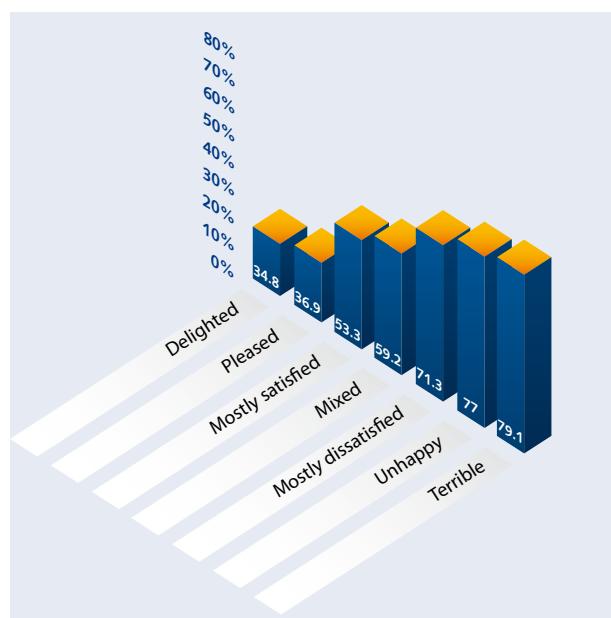


Figure 11: Stigma and overall quality of life (100)

and reported that perceived stigma was fourth in importance in predicting quality of life, after psychological distress, loneliness and adjustment. Stigma accounted for twice the amount of variance in quality of life scores as did clinical variables such as seizure frequency and antiepileptic drug side-effects. There is obviously a cultural element to the experience of epilepsy stigma, as evidenced in the European-wide study cited above (114). The authors reported wide differences in levels of 'felt' stigma across eight western European countries, with percentages positive for stigma ranging from 32% in Spain to 66% in France. Overall, 51% of respondents reported feeling stigmatized by their condition, 18% being 'highly' stigmatized. Using the same measure, Herodes et al. (121) reported similar proportions of persons in a study conducted in Estonia.

Surveys in the United Kingdom suggested that health care for people with epilepsy is fragmented and inadequately resourced, many patients receiving care that is substandard in relation to published guidelines (122,123). The widely varying levels of provision of epilepsy care across Europe (41) might in part be a reflection of the varying degree of stigma associated with the condition. Significant levels of dissatisfaction with the quality of their medical, social and educational care have been expressed by people with epilepsy (124). Nevertheless, it has been concluded (125) that the levels of disability and social exclusion of people with epilepsy could be considerably lessened by relatively simple and inexpensive changes in the delivery of their care.

Trostle (126) commented that 'to have epilepsy is to open oneself to the full force of past and contemporary social prejudice and misunderstanding.' His emphasis on the prejudices held by others links to the work of recent stigma theorists (127, 128), who have reframed the concept of stigma to focus less on the person who is stigmatized and more on those who stigmatize.

Public attitudes to epilepsy across Europe are highlighted by parallel studies conducted from the early 1980s (129-133), finding for example widely

varying levels of public affirmation to the question about children with epilepsy, ranging from 27% in Italy in the 1980s to 6% in the Czech Republic in the early 2000s (134, 135). A public survey of attitudes to epilepsy conducted as part of a national 'omnibus' survey in the United Kingdom found that most persons who took part were well-informed about epilepsy and held attitudes that were highly favourable towards those affected. There were, nonetheless, important knowledge and attitude gaps, with clear potential for discriminatory behaviour. In the same year in Austria, nearly one-tenth of respondents expressed negative attitudes towards people with epilepsy, a sufficiently large proportion, in the authors' view, that 'most patients will be confronted with them on a regular basis.' (133)

Nevertheless, small but significant temporal improvements in public attitudes have been noted in European studies. For example, Mernics et al. (132) compared public attitudes to epilepsy in Hungary across a 6-year period during which national initiatives to promote the integration of people with epilepsy were instigated. They were able to report improvements in expressed attitudes in relation to three questions regarding association with a child with epilepsy, marriage to a person with epilepsy and employment of a person with epilepsy. Likewise, changes were found in public attitudes to epilepsy in the Czech Republic over a 16-year period and showed that familiarity with epilepsy was significantly higher in 1997 than in 1981; intolerance towards people with epilepsy (as measured by a similar question set) had fallen (134); and knowledge about epilepsy as a condition of ill health had risen. Despite these findings, both studies concluded that the situation for people with epilepsy is still less than satisfactory.

There are two distinct ways of working to reduce the stigma of epilepsy in Europe. The first relates to people with epilepsy themselves, who need support to counter prevailing negative stereotypes and reduce their experience of stigma. One way this can be accomplished is through 'identity politics' (136). Although people with epilepsy may have been slower than some other stigmatized groups to respond to the political call, epilepsy associations

are moving rapidly from providing support and information to an increasingly political and campaigning role, agitating for better services and less discrimination for their members (137).

At the same time, campaigns such as the Global Campaign Against Epilepsy (138) are raising the profile of the disorder with governments and their health system planners and providers. Another way is to support people with epilepsy individually to develop resourcefulness and resilience in putting the stigma of their condition aside. A critical factor here is increased knowledge, as the lack of it can increase a sense of stigma on the part of affected persons (139, 111). Targeted educational programmes and counselling for people with epilepsy and their families are therefore clearly indicated.

Initiatives are also required that focus on changing negative public attitudes. A number of strategies have been proposed, including education and information provision, advocacy and increasing the level of contact between people with epilepsy and people without epilepsy. A good example of advocacy at work in Europe is the group in the United Kingdom, 'Epilepsy Bereaved', whose work stimulated the Department of Health to commission the first audit into epilepsy-related deaths in the country (140), which led to a series of recommendations for the care of people with epilepsy. Another example, in this instance of an intervention based on increasing contact, is the 'Horizon' initiative in the Netherlands (141), in which people with epilepsy are placed in employment to expose employers to them as employees. The success of such initiatives suggests that much can be done to reduce the experience of stigma among people with epilepsy living in Europe, and so lessen the burden of their condition.



### 3. Legislation

People with hidden disabilities, such as epilepsy, are among the most vulnerable in any society. Jacoby in the United Kingdom (142) stated that all chronic diseases affect quality of life but epilepsy has a greater impact. People with epilepsy are vulnerable because of the disorder itself and because of the stigma attached to it.

Stigmatization leads to discrimination, and people with epilepsy experience prejudicial and discriminatory behaviour in many spheres of life and across many cultures (143).

People with epilepsy also experience limitations to their enjoyment of economic, social and cultural rights. They have many unmet needs in the areas of civil rights, education, employment, residential and community services, and access to appropriate health care (142). Research into the vocational interests of people with epilepsy shows that they are often advised not to undertake their training of choice because of the suspected consequences of having epilepsy. Job restrictions are still very common in all European countries. For instance, severe epilepsy-related job restrictions were found in the records of the Berlin Labour Exchange, which were in sharp contrast to the consistent reports of low accident rates among people with epilepsy (144).

The restrictions on full participation in community life can marginalize people with epilepsy from society. For example, ineligibility for a driving licence frequently imposes restrictions on social participation and choice of employment, and failure to secure insurance protection leaves people with epilepsy unnecessarily exposed to risks that largely have no bearing on their condition. Discrimination in access to education is not unusual for people affected by the condition (145).

Refusal of and restrictions to obtaining insurance are not limited to developing countries. It has been (146) reported that as much as 36% of people with epilepsy in the United Kingdom were refused one or more types of insurance (146). This discriminatory behaviour becomes a restriction on the right to make adequate financial provision in guarding against risks to the individual and his or her family.

Civil and human rights violations are more evident in developing countries, especially those that have a history of generalized rights abuse. While specific practices vary from country to country, however, discriminatory attitudes and prejudicial behaviour towards people with epilepsy are common around the globe.

Legislation is an important means of addressing these problems and challenges. Well-crafted legislation based on internationally accepted human rights standards can prevent violations and discrimination, promote and protect human rights, enhance the autonomy and liberty of people with epilepsy and improve equity in access to health care services and community integration. Legislation can serve to legally enforce the goals and objectives of policies and programmes related to epilepsy. The right to equal treatment is clearly described in law (United Nations and European Union Treaty of Amsterdam, 1999) and deserves the protection by enforceable legal remedies. Accordingly, strategies aimed at promoting the social and professional integration of people with epilepsy and at rooting out the prejudice they encounter should be secured and underpinned by equal opportunities legislation. Such legislation should render it illegal to treat people with epilepsy less favourably than others, unless clear justification for doing so can be proven. Blanket restrictions and barriers automatically generated in response to epilepsy should be prohibited. The principle that people are entitled to individual assessment of their abilities and the risk they present to others should be endorsed by law (147).

The current reality, however, is that the laws that affect the lives of people with epilepsy are often outdated. They frequently fail to promote and protect human rights adequately, and they sometimes actively promote the violation of rights. In many countries, there is a total absence of protective legislation, and there are ample examples of legislation based on centuries of stigmatization.

WHO has been involved in reaching consensus about the rights of patients in general. Especially important was a European consultation held in

Amsterdam in March 1994 under the auspices of the WHO Regional Office for Europe ([www1.umn.edu/humanrts/instre/patientrights.html](http://www1.umn.edu/humanrts/instre/patientrights.html)), shortly before the publication of a booklet on the topic (148). It described a number of trends in the evolution of patients' rights:

- legislators were slow in taking initiatives to promulgate general laws on the rights of patients, and legislative activity was usually restricted to specific situations, such as experiments on human beings and involuntary admission of patients to mental institutions, although patients' rights were sometimes included in administrative regulations, such as those for certification of hospitals
- the introduction of new patients' rights, like the right to privacy and the right of access to medical records
- to reformulate legal provisions previously regarded as doctors' duties into patients' rights. The authors gave the example of professional secrecy, which is now seen as patients' right to confidentiality
- fourth was a trend towards new procedures for the protection of patients' rights in Europe, in which complaint procedures were established and tested in several European countries
- legislation on experiments on human beings has been increasing since the 1970s. One motive for interference by legislators was the involvement of third-party interests in the relationship between a doctor and a patient in experiments carried out during treatment
- renewed interest in the rights of psychiatric patients admitted involuntarily is an issue still not settled as late as 2004
- lastly, although legal provisions, mostly in civil law, allow for guardianship (or tutelage) of mentally retarded adults, some countries were considering the introduction of new forms of protection for such people.

### ■ 3.1 Driving

In most societies the right to drive is a vital component of an acceptable quality of life and is therefore important for persons with epilepsy. Driving enlarges the potential for both work and leisure. People without a driving licence have difficulty in finding an appropriate professional job.

The European region can be divided generally into two with regard to the importance of driving. Rapid equality can be expected as a consequence of developments over the past few decades, including the harmonizing effect of the European Union.

Driving licences are of great importance in the so-called post-socialist countries, not only because of its practical advantages but also from the point of view of the car as personal property and driving as an activity representing wealth, a comfortable life and a luxury. Therefore, the right to drive is one of the most important components of quality of life. The proportion of persons with epilepsy who have a driving licence is, however, much lower (44%) than that of the general population (67%), as shown in seven European countries (149).

If epilepsy is considered (incorrectly) as one illness, the risk of dangerous seizures accompanied by loss of consciousness would exclude driving by any person with this condition. Driving licence restrictions are based on the assumption that epilepsy creates a risk for road traffic accidents; however, no prospective population-based studies have been reported. A population-based retrospective cohort study (150) found that the road traffic accidents ratio was 1.33 ( $p = 0.04$ ) for persons with epilepsy. A retrospective study was conducted in the United Kingdom (151) in which the answers to self-completed questionnaires from 8888 normal drivers were compared with those from 16 958 drivers who had notified the authorities about a single epileptic seizure or diagnosed epilepsy. No overall differences in total road traffic accident rate were found, but the rate of serious injuries was 40% higher in the epilepsy cohort, and there was evidence of a twofold increase in non-driver fatalities. The study design, a retrospective questionnaire, makes it impossible to evaluate driver fatalities. General statistics on car accidents involving persons with epilepsy show an increased risk, although it is lower (0.1-0.3%) than that associated with alcohol (6-9%). In such surveys, however, no distinction is made between accidents caused by persons with epilepsy with and without a driving licence and persons in whom the first symptom of epilepsy occurred at the time of the accident. These statistics are therefore not informative about the real risk for traffic accidents of persons with epilepsy.

who are driving legally.

Indirect data in fact indicate that such people have a better safety record. In an analysis of the legal issues associated with traffic events, the proportion of persons with epilepsy was much lower than that of persons without epilepsy, and in two-thirds of cases the cause of the accident was not the seizure (152). This might be explained by the fact that driving and retaining a driving licence are generally more important for persons with epilepsy, so that they do not drive aggressively, do not drink alcohol and respect the rules. Over-restrictive regulations, however, can result in non-compliance and concealment of the diagnosis. Therefore, serious accidents are more often caused by persons with epilepsy who are driving illegally.

### Driving regulations

All European countries have restrictions for people with epilepsy when it comes to driving a power-driven vehicle. Although there is a European Union directive (European Council, 1991), legislation and practical implementation of restrictions vary considerably among Member States. In a number of European countries, the responsibility for informing the authorities that a person has epilepsy lies with the treating physician. There have been no studies of how physicians fulfil this obligation, but there is a strong sense among neurologists that underreporting is common. In the United Kingdom, the responsibility for informing the authorities lies primarily with the patient, but less than one-third of persons who were expected to self-report their epilepsy or attacks of loss of consciousness actually did so (154). The underreporting of epilepsy or seizure frequency by patients and physicians obviously creates a possible selection bias in studies of road traffic accident rates associated with epilepsy.

The day-to-day situation in Europe is still not ideal. Evaluation of the driving ability of a person with epilepsy varies widely among both physicians and patients, mainly due to lack of knowledge about epilepsy. A large questionnaire study of European national regulations for issuing driving licences to persons with epilepsy (155) showed that two countries impose a permanent ban for persons

with epilepsy. A seizure-free interval of 12 months in seven countries and of 24 months in 13 other countries is required for issuance of a licence to drive (at the non-vocational level). In 14 countries, the restriction depends on the type of seizure, and in others special boards assess each problematic case.

Current legislation in most countries permits people with epilepsy who have controlled seizures to obtain a driving licence. These laws are an attempt to balance the important economic and social value of driving with the risk to public safety from seizure-related crashes. Various clinical factors are considered in these laws, but the length of the prescribed seizure-free interval is the dominating factor. Restrictions still vary considerably, however, among the Member States of the European Union.

With the support of the European Commission, this led to the formation of European workshops on driving licence regulations in May 1995 and March 1996 organised by the International League Against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE) (65). After the 1995 / 1996 workshops, national legislation was adapted to an important degree in several European countries, but remained unchanged in others. This situation led to a renewed call for harmonisation. The Advisory Commission on Epilepsy and Driving to the Driving Commission of the European Commission sought a scientifically based platform, by appointing an expert working force, for formulating a set of rules, common to all Member States, regarding definitions, road traffic accident risk rates and consequent driving restrictions that accommodate both public road safety issues and personal integrity for persons with epilepsy. The European Directive 209 / 112 EC came into law on the 29th August 2009. The Directive puts into force the recommendations on Epilepsy and Driving of the expert working force which reported to the European Commission in 2005.

The regulations provide for a 1 year seizure-free period for Group 1 vehicles (cars, vans, motorbikes). For some member states, such as France and the Netherlands, these new regulations may mean that PWE are worse off than before because the seizure-

free period can be shorter at present there. For PWE who wish to drive Group 2 heavy goods vehicles (buses, lorries etc.) the new Directive may offer some hope. In many countries there is a total ban on anyone who has had a seizure driving these types of vehicles but under the new regulations, someone with epilepsy who has been seizure-free and off all anti-epileptic drugs for 10 years or more, may apply for a licence.

European Union member states have up to one year to introduce new legislation or amend existing

driving in line with the Directive. For many of the member states who gained access to full membership of the EU in the recent past, this may represent a huge change as some of these countries as many have no legislation and operate blanket bans on driving by people with epilepsy (PWE). In general, these sorts of bans lead to many more PWE driving who should not because of the unfairness of the total prohibition, than in other countries.

Most EU countries will have to amend their existing legislation to reflect these changes.

## 4. Professional and public education

### 4.1 Professional education

Good education of professionals dealing with epilepsy is pivotal for the quality of epilepsy care. Primary education in whatever field of health cannot include much more than the basic facts, to prevent, if possible, the worst mistakes. Specialization, e.g. of a medical doctor as a neurologist, typically involves postgraduate education, which in most countries is organized publicly in one way or another. It is however, rare, that a public system includes specialization in a field as specific as epileptology, and the expertise that is required to deal with other than the most straightforward cases must usually be acquired elsewhere. Such specialization has become increasingly important as a consequence of both the rapid development of drugs and the growing awareness of epilepsy as a worldwide health problem. As high-quality epilepsy care should be made available everywhere, professional education is now a high priority.

Education is one of the main objectives of ILAE, and many of its national chapters have set up their own educational programmes, particularly in Europe (figure 12).

In the 1990s, efforts were made to extend excellent local initiatives to an international level. The first step was taken by the ILAE Commission on European Affairs, which in 1996 founded EUREPA (European Epilepsy Academy), and designed a curriculum

for certification of doctors as epileptologists. In principle, the certificate requires spending 18 months in training institutions: 12 months in a core curriculum including clinical epileptology, EEG, imaging and clinical pharmacology and six months on three to six elective subjects chosen from a list of 11; on-site training in electives can be replaced by participation in courses that give credit points as time equivalents. Existing educational programmes were examined and new initiatives taken, and epilepsy centres and educational institutions joined an educational network. The credit point system is in place and being used. EUREPA was responsible for the educational courses at European and international epilepsy congresses, and regional academies have been set up in Asia and Oceania and the Latin American Region, which cooperated with EUREPA and conducted their own regional programmes, reaching out to countries that do not yet have League chapters.

An important activity of the Academy was a series of train-the-trainer courses (in English, French, German and Italian), at which over 85 participants from more than 40 countries became acquainted with modern didactic methods. These trainers have since organized and conducted epileptological education in their countries and languages. Although this was a European initiative, a course in French was offered to participants from francophone Africa. This was followed by a course in Portuguese with participants from Portugal, Brazil and three African countries. The trainers' local activities brought about a certain shift of focus in the Academy's agenda. Whereas it was initially set up to establish a group of highly specialized epileptologists, it got more concerned with disseminating comprehensive, up-to-date knowledge about epilepsy to the secondary sector (such as neurologists and paediatricians) and even to the primary sector of health care.

In large populations, primary health care is not exclusively provided by physicians, and, in many countries, especially in rural areas, the first medical contact for a person with epilepsy will be a nurse or another member of the auxiliary health force. In other countries, professions allied with medicine, such as social workers, nurses, psychologists and

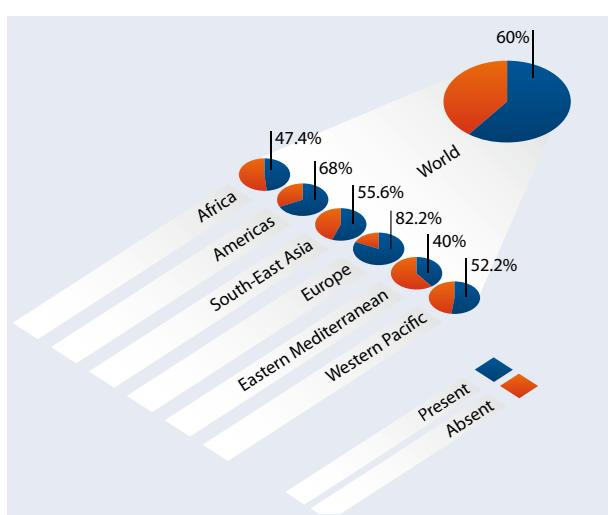


Figure 12 Training in epileptology in WHO regions and the world (Atlas: Epilepsy Care in the World 2005)

ergotherapists, are active in comprehensive care programmes for persons with epilepsy. EUREPA thus got involved in epileptological education for professions allied with medicine, in collaboration with the European IBE Commission. As a first step, interdisciplinary courses were planned to provide the knowledge that anyone who works professionally with persons with epilepsy should have. Language is more of an issue in this situation than for medical doctors, who now in many parts of the world often know English well enough to follow educational activities in that language.

While ILAE considers it important to attract young talent to the field by providing good possibilities for training and research, cost is a problem. Many people who are interested in participating in educational courses and could benefit from them cannot afford to go to international meetings or spend time in a leading epilepsy centre. ILAE regional commissions have taken initiatives to address this problem. In Europe, scholarships are provided for various educational activities under the ILAE banner, and a large number of bursaries are made available for young researchers to attend the European congresses of epileptology, on the basis of need and submission of a high-quality scientific contribution.

The Asian Academy has also established several scholarships for on-site education in the region.

At a global level, ILAE has started a series of advanced educational summer courses in Venice, Italy, where young epileptologists study a certain field of epileptology in depth, under the guidance of and in interaction with a faculty of the best international experts. Here again, bursaries allow the participation of people who otherwise could not afford to attend. Meanwhile, three additional advanced courses were set up in Europe and one in Latin America.

Although these activities have much improved the access of young people to the field of epilepsy, they are not sufficient to meet the existing demand. Therefore, EUREPA started a programme of distance learning. Distance learning is less expensive than on-

site education, although the highly interactive course requires much more tutorial resources. Interactive advanced courses together with distance learning will make it possible to minimize the time spent in on-site training at an educational institution. We are moving towards an educational system where on-site training, advanced courses and distance education are interlinked to ensure access to high-standard expertise in epilepsy care in all parts of the world.

## ■ 4.2 Public Education

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The social consequences of having epilepsy can be enormous, although they vary from country to country based on cultural differences. These difficulties are often not related to the severity of the condition, but stem from the concept of epilepsy as held by the general public and sometimes by the people with epilepsy themselves. This was recognised by Dr. Richard Masland a former secretary general of IBE who stated: "Unfortunately, pre-occupation with the control of seizures, both on the part of the physician and the patient, often seems to overshadow an adequate concern for the other factors. Yet in terms of disability, for many patients it is these other factors, which determine whether they will or will not make a satisfactory life adjustment".

Organisations concerned with raising awareness about epilepsy must choose the appropriate core message, define their target audience and how best to communicate this message. Such target groups encompass:

- national and local governments: in order to create or change laws to eliminate economical burdens concerning treatment
- the general public, including teachers: to change attitudes towards epilepsy and people who have the condition
- the professionals: including traditional healers, to enhance and improve the treatment of people with epilepsy worldwide
- the person with epilepsy and the family, concerning the concept of epilepsy, its causes, its treatment, diagnosis and consequences for the future.

Public education programmes may be generic, as in campaigns aimed at the widest possible audience, or targeted at a more specific audience such as teachers, employers, social and community services (153). Methods of delivery will vary relative to the needs of the audience. A more targeted approach could comprise strategies such as conferences and seminars, workshops and study days. Information materials can be developed with the needs of different professionals in mind (e.g., packs for nursing and paramedical staff, doctors, primary and post primary teachers, employers and trainers). Information in printed form such as booklets and leaflets, can be disseminated to the public through

public information access points such as libraries, pharmacies, citizens' information centres, and social and community advisory services (154).

In conclusion:

- public education about epilepsy is a priority objective of all patient organisations
- public education is essential to tackle the myths and misunderstandings that surround epilepsy
- the needs of the target audience must be assessed when devising education strategies
- ongoing assessment of public education programmes is necessary to refine strategies further.

## 5. Research

Epilepsy is a serious, common neurological disorder characterized by recurrent seizures due to abnormal synchronized neuronal discharges. Our understanding of epilepsy has come a long way since Hughlings Jackson started his research 150 years ago. The risk factors and epileptogenic mechanisms for the different types of epilepsy have been correlated with their prognosis, thus making it possible to establish therapeutic strategies based on pharmacological agents or surgical procedures. Nevertheless, in 30-40% of cases, epilepsy is not satisfactorily controlled by the available remedies, and a non-negligible proportion have a poor prognosis in terms of both the severity of the epilepsy and its psychosocial outcome.

The main challenges that research on epilepsy is presently facing are:

- to prevent the unfavourable evolution of early-onset severe epileptic encephalopathy (e.g. West syndrome)
- to identify in their early stages those lesional epilepsies the poor outcome of which can be predicted and prevented by appropriate pharmacological or surgical procedures
- to find new, more effective antiepileptic and antiepileptogenic pharmacological agents capable of counteracting the course of epileptogenic processes that eventually lead to chronic severe epilepsy
- to define the role of epilepsy genes in the pathogenesis of putatively purely genetic epilepsy (idiopathic epilepsies) and of cryptogenic forms that might be due to interaction between genetic and environmental factors.

The European epileptology community has an important tradition of scientific research, contributing one-third of worldwide scientific publications in the field, however, it 'lacks central coordination'.

In 2005, EPICURE, an integrated multidisciplinary project coordinated by G. Avanzini (Milan, Italy), was set up to coordinate the work of 30 research groups in 14 European countries working on epileptogenic mutations, epilepsy-related plasticity, epilepsy-associated developmental disorders and

therapeutic strategies. This project was based on epidemiological observations that have led to a consensus that genetic factors play a central role, especially in so-called idiopathic generalized epilepsies, and that maladaptive developmental processes also contribute to the development of epilepsy. Precisely what genetic factors are involved and how they interact with developmental alterations are far from established. Moreover, their implications for understanding the principles of drug and other treatments of epilepsy are poorly understood.

Another interesting example of a collaborative multi-centre study is EURAP, an international registry of antiepileptic drugs and pregnancy coordinated by T. Tomson (Sweden), D. Battino (Italy) and E. Perucca (Italy). The study was started in 1999 by several European groups with experience and interest in maternal and fetal well-being associated with maternal use of antiepileptic drugs. EURAP is a prospective and retrospective observational study. It has since been expanded to interested countries outside Europe.

## 6. Initiatives to address - the European region

### ■ 6.1 The Global Campaign Against Epilepsy

As the world's most common brain disorder, epilepsy affects some 50 million people worldwide, 85% of whom live in developing countries. Epilepsy is a global problem affecting all ages, races, social classes and countries. Epilepsy imposes enormous physical, psychological, social and economic burdens on individuals, families and countries, especially due to misunderstanding, fear and stigma.

Globally:

- 250 000 000 people have one seizure in a life time
- 2 500 000 new cases of epilepsy occur each year;
- 70% of people with epilepsy could be seizure-free with (cheap) treatment
- 80% of people with epilepsy do not receive a proper diagnosis and are not properly treated.

In response to these challenges ILAE and IBE have joined forces with WHO for a campaign of concerted action to address the common but neglected global problem of epilepsy.

The Campaign's mission statement is to improve the acceptability, diagnosis and treatment, services and prevention of epilepsy worldwide. The Campaign's strategy has two parallel tracks:

- raising general awareness and understanding of epilepsy, for instance by organizing regional conferences on public health
- supporting departments of health in identifying needs and promoting education, training, treatment, services, research and prevention nationally, by initiating demonstration projects.

The Campaign's objectives are:

- to reduce the burden of epilepsy by decreasing the treatment gap and promoting the inclusion of epilepsy care in national health care plans
- to improve understanding of epilepsy
- to promote primary and secondary prevention of epilepsy
- to improve medical, social and psychological care for persons with epilepsy
- to reduce the limitations encountered by people with epilepsy and their families.

The Campaign's ultimate objective is to ensure

that governments and health care providers place epilepsy on the health and development agenda in order to formulate and implement cost-effective responses to epilepsy. The indicators of its success will be the proportion of targeted countries that have implemented reforms in epilepsy care and the number of countries that have increased their budget for epilepsy care.

The strategic approach of the Campaign is dissemination of information on the magnitude, burden, diagnosis and treatment of epilepsy as well as information on available resources; support to governments and health care providers in formulating and implementing comprehensive services, by offering successful models of epilepsy care; support to countries in fighting stigma and discrimination and support for research capacity in developing countries.

The Campaign was launched at WHO Headquarters in Geneva, Switzerland, in June 1997 and in Dublin, Ireland, in July of the same year during the 22nd International Epilepsy Congress. During the first three years, the Campaign concentrated mainly on increasing awareness, creating acceptance and improving education, including within the League, Bureau and WHO themselves. The most important achievement during that period was the acceptance of the Cabinet Paper on the Global Campaign in December 1999, which raised its status to one of the highest priorities of WHO (Annex II).

The experience of the first phase of the Campaign gave the rationale for the second phase, with the new, more ambitious goal of improving health care services for treatment, prevention and social acceptance of epilepsy worldwide. The second phase of the Campaign was launched in Geneva on 12 February 2001 in the presence of the Director General of WHO all six WHO Regional Advisors, representatives of 13 missions of WHO Member States, 24 national organizations that were members of IBE and ILAE, four nongovernmental organizations for neuroscience or neurology and 17 representatives of the private sector.

On a global level, the main activities of the

Campaign include:

- assisting with the organisation of regional conferences and the development of Regional Declarations
- organizing sessions during International Congresses
- preparing/assisting with publications, including Newsletters
- coordinating Demonstration Projects
- assessing Country Resources
- assisting with the Regional Reports
- assisting with the development of evidence based guidelines
- (assisting with) Fundraising.

### The Campaign in Europe

In Europe, 6 million people have epilepsy, and 15 million will have at least one seizure during their lives (1). In some countries of Europe, epilepsy is still not recognized as a brain disorder, and up to 40% of people with epilepsy may be untreated, representing the treatment gap.

Professionals treating people with epilepsy often do not have sufficient specialized knowledge about the condition. In some countries, antiepileptic drugs are not always available or are unaffordable. In a number of European countries, diagnostic facilities are lacking or inadequate.

Campaign activities in the region include: the organization of a regional conference, formulation of a 'Declaration on Epilepsy', data collection on country resources for epilepsy, development of a regional report on epilepsy, drawing up evidence-based guidelines, initiation of a demonstration project, initiation of a project on stigma and of a project on legislation, meetings with WHO regional advisors for mental health and activities at regional, national and local levels.

### Regional conferences

Regional conferences on the public health aspects of epilepsy were organized in the African Region, the Region of the Americas, the South-East Asia Region and the Western Pacific Region jointly, the Eastern Mediterranean Region and the European Region. The aims of these conferences were:

- to adopt regional declarations on epilepsy, calling on governments and health care providers to take strong, decisive action to meet the objectives of the Campaign
- to promote the creation of regional white papers on epilepsy as detailed public health statements with appropriate recommendations for political action.

More than 1200 representatives from IBE, ILAE and WHO, other United Nations agencies and nongovernmental organizations, governments, universities and health care providers from over 130 countries, representing millions of people with epilepsy, participated in these conferences.

The first of these conferences took place in Heidelberg, Germany, on 25 October 1998 and was organized by Professor Peter Wolf. Over 100 leaders of European professional and lay bodies, WHO representatives and health experts from governments and universities participated. This conference resulted in the first Regional Declaration on Epilepsy and was unanimously adopted by all participants. (Annex (I)).

The next step was publication of a White Paper on Epilepsy, which was written by a number of epilepsy experts and professional bodies across Europe, under the aegis of EU CARE (European Concerted Action for Research in Epilepsy - a joint project of ILAE and IBE). The aims of the White Paper were to create awareness, educate, inform, influence and shape opinions about epilepsy at the heart of European political institutions. It was launched in the European Parliament in March 2001 and was endorsed by the WHO Regional Office for Europe.

**Organising sessions during International Congresses and Preparing/assisting with the development of publications, including Newsletters**

In order to raise awareness for the Campaign, for epilepsy in general, the treatment gap and the social, cultural and economic burden for people who have this condition, their relatives and society as a whole many sessions have been and are being organised during international congresses, among others during the bi-annual European ILAE and IBE congresses. Campaign articles have been published

in peer reviewed journals on the results of the Demonstration Projects and a number of stand-alone publications were prepared.

### Demonstration projects

A demonstration project has been initiated in Georgia to illustrate good practice in providing services to people with epilepsy. The models that will be developed will be used to show what can be achieved, what has been established and what is being initiated in many countries.

### Questionnaire on country resources for epilepsy

A questionnaire on country resources was designed by a group of experts to map the resources for epilepsy worldwide. Data was collected from key persons identified by official delegates of member chapters of ILAE/IBE or WHO regional and country offices. Countries were grouped into the six WHO regions and four World Bank income categories. The information is presented in 4 broad sections; Epilepsy: the disorder; the services; the care-providers and the public health aspects. The data included is organized in 17 themes and is presented as graphics, world maps and written text. Forty five out of the fifty three European countries completed this questionnaire, and the outcomes of the survey for Europe are included in this report as well as in the Atlas: Epilepsy care in the world (49).

### Evidence-based guidelines

Guidelines for the treatment of epilepsy in childhood and adolescence are being drawn up in collaboration with the WHO Department of Child and Adolescent Health and Development. The WHO Collaborating Centre - Oasi Centre in Troina, Italy has taken the lead. It is hoped that guidelines for neonatal seizures will also be available soon.

### Project on stigma

Within the Campaign, a grant application for a pilot project on stigma in epilepsy was submitted to the Fogarty Foundation (National Institutes of Health, USA) by a group of European experts under the leadership of A. Jacoby, University of Liverpool, United Kingdom, which was subsequently awarded. This project involved ethnographic studies to explore prevailing beliefs and attitudes to epilepsy in two

developing countries. The project defined theoretical models of stigma and its link to disease burden. Validated, culturally specific measures of outcome were formulated for use in future intervention studies. Throughout its implementation, the project enhanced social science capacity in the participating countries and facilitated strong collaboration for future research.

### Project on Epilepsy and Legislation

Within the framework of the ILAE/IBE/WHO Global Campaign Against Epilepsy a project on "epilepsy and legislation" was developed with the aims to:

- identify key human right issues that are being overlooked and need to be addressed at national/ regional levels
- develop an effective reference guide for professionals working in the area of epilepsy, lawyers and policy-makers as well as advocacy and human rights organisations working in the interest of people with epilepsy at national as well as international levels
- provide instruments for advocacy and lobbying to improve human rights conditions for people with epilepsy
- provide useful tools to reform laws and regulations related to epilepsy thus leading to better care and services and improved living conditions for people with epilepsy throughout the world
- increase awareness among people with epilepsy of the possibilities for better reintegration into society. It will help in reducing discrimination and stigma associated with epilepsy.

Specific objectives of the Project were to undertake a study to determine the existence and effectiveness in countries of legislation that address discrimination and promotes and protects the human rights of people with epilepsy. The study was performed done in the form of a survey. A questionnaire was developed including the following areas:

- health/health care (including health and life insurance)
- education
- employment
- civil rights (driving, marriage, divorce and annulment, sterilisation, adoption, housing, etc)
- criminal responsibility

- military duties
- religious duties, and
- any other relevant areas.

On the basis of this data, the state of 'epilepsy and legislation' in the selected countries were discussed. A proposal for a framework of good practice for 'epilepsy and legislation', sensitive to the resource setting was prepared.

#### **Meetings with regional advisors**

Members of the Campaign Secretariat met with WHO regional advisors for mental health on a number of occasions at WHO Headquarters in Geneva, Switzerland, during their annual meetings, in order to plan the activities of the Campaign for each WHO region.

#### **Regional activities**

Meetings with a number of Members of the European Parliament with a special interest in epilepsy took place on various occasions.

#### **National activities**

National activities in Europe range from translation of Campaign materials, to organizing poster campaigns, to discussions with health ministers, who on a number of occasions became involved and launched activities in their respective countries. Activities took place in about 70% of European countries, with media campaigns, articles and press, radio and television coverage.

#### **Future activities**

Many of the activities of the Campaign, such as the demonstration projects, are expanding both in size and in numbers. Furthermore, the focus of the Campaign has extended to the most vulnerable population groups in the developed world. In Europe, such populations may include communities of immigrants in industrialized countries and unemployed people who migrate from Africa and the Middle East to countries such as France, Germany, Italy and Spain.

## 7. Challenges

Major challenges for epilepsy in the European Region were included in the European Declaration:

- improving public understanding of epilepsy and thereby reduce its stigma
- removing discrimination against people with epilepsy in the workplace
- helping people with epilepsy to understand their condition and to empower them to seek appropriate treatment and lead fulfilled lives
- improving the knowledge of health care professionals and other professionals about epilepsy, before and after graduation
- ensuring the availability of modern equipment, facilities, trained personnel and the full range of antiepileptic drugs, so that an accurate diagnosis can be made leading to the most effective treatment
- stimulating research on epilepsy and its management
- encouraging close liaison among governments, health and social authorities and agencies, and the national chapters of the ILAE and IBE
- supporting the publication of a European White Paper as a detailed public health statement on epilepsy in Europe
- providing practical assistance for countries with underdeveloped epilepsy services within and beyond Europe.

### Improving public understanding

Although small but significant improvements in public attitudes have been noted in European studies (132, 134), the situation for people with epilepsy is still less than satisfactory.

There are two distinct ways of working to reduce the stigma of epilepsy in Europe. The first relates to people with epilepsy themselves, who need support to counter prevailing negative stereotypes and reduce their experience of stigma. The other focusses on changing negative public attitudes aiming at specific target groups. Potential strategies encompass, amongst others, education and information provision, advocacy and increasing the level of contact between people with epilepsy and people without epilepsy. Successful examples of initiatives addressing people with epilepsy and employers are described on page 37.

### Removing discrimination

People with hidden disabilities, such as epilepsy, are among the most vulnerable in any society. While the vulnerability of people living with epilepsy is due partly to the disorder itself, the stigma associated with the disorder brings a susceptibility of its own. Stigmatization leads to discrimination and people with epilepsy experience prejudicial and discriminatory behaviour in many spheres of life and across many cultures (143).

Legislation is an important means of addressing these problems and challenges. Well-crafted legislation based on internationally accepted human rights standards can prevent violations and discrimination, promote and protect human rights, enhance the autonomy and liberty of people with epilepsy and improve equity in access to health care services and community integration. Legislation can serve to legally enforce the goals and objectives of policies and programmes related to epilepsy.

The current reality, however, is that the laws that affect the lives of people with epilepsy are often outdated. They frequently fail to promote and protect human rights adequately, and they sometimes actively promote the violation of rights. In many countries, there is a total absence of protective legislation, and there are even examples of legislation based on centuries of stigmatization.

Within the framework of the GCAE, a project on "epilepsy and legislation" was developed to collect information from countries all over the world concerning existing legislation and regulations related to epilepsy in order to review the comprehensiveness and adequacy of these legal measures in promoting and protecting the rights of people with epilepsy.

### Empowerment of patients

In the developed world, up to 70% of people with epilepsy have a condition that is well controlled by medication. For most people with epilepsy in Europe, the problem is not the condition itself but the associated difficulties it creates in relation to education and schooling, employment, driving, pregnancy and other women's issues, and insurance.

For many people with epilepsy, the greatest problems they face are due to the stigma, which is caused by lack of public awareness about the condition.

Most lay epilepsy organizations in Europe address all the above issues and provide support for persons with epilepsy, their families and those who care for them from the moment a diagnosis of epilepsy is made. The services provided by lay organizations are limited only by the available funding. In some countries, an association is eligible to apply for a government grant or might receive such funding automatically, while in others the provision of services depends on the success of dedicated fundraising activities.

In respect to educational activities, epilepsy organizations target two audiences: people with epilepsy and the general public. As the stigma associated with epilepsy can cause more distress than the condition itself, one of the main objectives of all epilepsy organizations is to raise public awareness and knowledge. This is achieved through public information campaigns in schools, places of employment and shopping centres, with information leaflets and posters. Information is also published in interviews and articles in newspapers and magazines and on radio and television.

To give people with epilepsy comprehensive information on their condition, organizations provide a range of information materials to their members, including newsletters, information booklets and leaflets, videos and DVDs, and most have a well-maintained website.

#### **Improving professional knowledge of epilepsy**

The International League Against Epilepsy published a document on "Appropriate standards of epilepsy care across Europe". Professionals treating people with epilepsy often do not have sufficient specialised knowledge about the condition. In some countries, antiepileptic drugs are not always available or are unaffordable. In a number of European countries diagnostic facilities are lacking or inadequate. Good education of professionals dealing with epilepsy is pivotal for the quality of epilepsy care.

Specialization, e.g. of a medical doctor as a neurologist, typically involves postgraduate education, which in most countries is organized publicly in one way or another. It is rare, however, that a public system includes specialization in a field as specific as epileptology, and the expertise that is required to deal with other than the most straightforward cases must usually be acquired elsewhere. Such specialization has become increasingly important as a consequence of both the rapid development of drugs and the growing awareness of epilepsy as a worldwide health problem. As high-quality epilepsy care should be made available everywhere, professional education is now a high priority. Education is one of the main objectives of ILAE, and many of its national chapters have set up their own educational programmes, particularly in Europe (Chapter 4.4).

#### **Ensuring accurate diagnosis and effective treatment**

The ILAE Commission on European Affairs (a sub-commission on European guidelines) report on the provision of epilepsy care across Europe (41) showing that, despite large national and regional variations in the provision of epilepsy care, the same main problem areas occur across Europe. The problems were more pronounced in Eastern Europe, but even countries with the best epilepsy care lacked comprehensive care and epilepsy specialists, with stigmatization and social problems and lack of knowledge even within the medical profession. Lack of epidemiological data was one of the commonest problem areas. Although WHO and World Bank studies have shown that epilepsy is a considerable economic burden, very few European countries have national plans for epilepsy.

#### **Stimulating research**

The EU is spending € 6 billion on health research between 2007 and 2013 under the Seventh Framework Programme for Research and Technological Development (FP7). The objective is to improve the health of European citizens, and increase and strengthen the competitiveness and innovative capacity of European health-related industries and businesses.

The emphasis will be on the translation of basic discoveries into clinical applications, the development and validation of new therapies, health promotion and prevention, including healthy ageing, better diagnostic tools and medical technologies, and sustainable and efficient healthcare systems. Priority diseases will include cancer, cardiovascular, infectious, mental and neurological diseases, in particular those linked with ageing.

The ILAE Commission on European Affairs prepared a position paper on research priorities in epilepsy to be used as a tool for communication with the European Commission in order to obtain support for epilepsy research in Europe and include epilepsy research on the European Agenda (155).

### **Partnerships**

Partnership within and beyond the health system are essential to achieve a world in which no person's life is limited by epilepsy. Such partnerships encompass:

- non-Governmental Organisations (NGO's) in itself are partnerships, made up of individuals who have common goals and interests at heart
- partnerships between patients and professionals on a national, regional and global level in order to raise awareness for epilepsy and stimulate research
- partnerships between the patient and professional NGO's and WHO in order to decrease the treatment gap
- partnerships between patients, professionals and politicians, for instance to develop national healthcare programmes
- partnerships with foundations and charitable organisations, who support the work of the NGO's both financially and with human resources.
- partnerships with health care providers to try and improve the availability, accessibility and affordability of treatment
- partnerships with the private sector, especially in the pharmaceutical industry. After all, we all have a shared interest in that we want "...to improve epilepsy care throughout the world..." (quotation from a presidential message). Such partnerships should not be limited to pharmaceutical industries.

Partnerships are key elements for the success of interventions. Dr. Brundtland, a former Director-General of WHO, said, on the occasion of the Launch of the second phase of the Campaign (Geneva, Switzerland, 2001): "The collaboration between the International Bureau for Epilepsy, the International League Against Epilepsy and WHO has shown that when people with different backgrounds and roles come together with a shared purpose, creativity is released and expertise is used in innovative and constructive ways".

Partnerships, can and do bring progress!

### **Advocacy**

Advocacy has become more important over the past few years and now plays a major role in helping epilepsy organizations to improve their services. These organizations make regular representations to governments and health departments on a range of issues, both legislative and health service-related, to urge improvements in the level of services provided, such as for more specialist consultants, for free or reduced-cost epilepsy medication or for improved outpatient facilities. It is not unusual for organizations to encourage elected members of parliament with an interest in epilepsy to form lobbying groups to assist in this activity (Chapter 4.1). Regional declarations and White Papers are influential instruments, for instance in two Eastern European countries, Georgia and Kyrgyzstan, they have opened the doors to Health Ministers, bringing epilepsy into their national health plans. National epilepsy reports have also been published in Germany and Switzerland.

### **Assisting countries with underdeveloped epilepsy services**

Developing a relationship between people from countries with developing economies and people coming from countries with more developed ones is not easy and knows many pitfalls. Similarity and equality are vital for the success of mutual projects and a true two-way communication is essential. Achieving is not easy, as the "richer" party tends to give and guide, whilst the "poorer" party accepts

and must follow. This may create a situation that is, in fact, totally contradictory to the target: a partnership based on equality.

Important conditions for the success of the above relationships are:

- clearly define the project
- make a transparent plan of action, thus motivating all concerned
- make sure there are local contacts in the selected country to ensure communication
- equality should be inhibited in all projects
- projects should be beneficial to the local population whilst local collaborators should contribute to the overall goals.

Therefore when aiming for twinning, a great deal of creativity is needed. In the meantime, there are quite a few examples of partnerships between countries with developed services, providing practical assistance to countries with underdeveloped epilepsy services within and beyond Europe, that prove to be successful, for example the partnership between the Danish IBE member and the IBE member in Uganda.

## 8. Actions and recommendations

Epilepsy care in the European Region faces many challenges which should lead to subsequent recommendations. In the Region the following are recommended as priority areas for action:

- raise the profile of epilepsy within the European Community and work for changes in budgeting and policy-making relating to people with epilepsy
- develop and implement effective health policy initiatives to reduce the stigma of epilepsy
- collect information from countries about existing legislation and regulations associated with epilepsy in order to review the comprehensiveness and adequacy of these measures
- improve access to care for people with epilepsy
- make epilepsy surgery, which is potentially curative, more widely available
- establish more rehabilitation units in epilepsy centres across Europe
- promote and reinforce epilepsy research in the region
- stimulate studies of the economic aspects of epilepsy to allow more effective use of limited resources
- organize educational campaigns about epilepsy for the media and the public, for professionals and for people who have the condition.

**Raise the profile of epilepsy within the European community and work for changes in budgeting and policy-making relating to people with epilepsy**  
Advocacy has become more important over the past few years and now plays a major role in helping epilepsy organizations to improve their services. It is not unusual for organizations to encourage elected members of parliament with an interest in epilepsy to form lobbying groups to assist in this activity on a national basis.

The European Commission can help by co-financing research in collaboration with non governmental organisations. Besides the treatment gap, there is also the educational gap which can be addressed effectively with information. Here the European Commission has a flagship position to increase awareness through the Public Health Information Programme.

The Commission is inviting applications for projects from stakeholders and calls for proposals are issued on an annual basis. However, such proposals should be prepared regularly.

**Develop and implement effective health policy initiatives to reduce the stigma of epilepsy**

Targeted educational programmes and counselling for people with epilepsy and their families are clearly indicated, but this is not enough. Initiatives are also required that focus on changing negative public attitudes.

**Collect information from countries about existing legislation and regulations associated with epilepsy in order to review the comprehensiveness and adequacy of these measures**

Well-crafted legislation based on internationally accepted human rights standards can prevent violations and discrimination, promote and protect human rights, enhance the autonomy and liberty of people with epilepsy and improve equity in access to health care services and community integration. Legislation can serve to legally enforce the goals and objectives of policies and programmes related to epilepsy.

The right to equal treatment is clearly described in law (United Nations and European Union Treaty of Amsterdam, 1999) and deserves the protection of enforceable legal remedies. Accordingly, strategies aimed at promoting the social and professional integration of people with epilepsy and at rooting out the prejudice they encounter should be secured and underpinned by equal opportunities legislation. Such legislation should render it illegal to treat people with epilepsy less favourably than others, unless clear justification for doing so can be proven. Blanket restrictions and barriers automatically generated in response to epilepsy should be prohibited. The principle that people are entitled to individual assessment of their abilities and the risk they present to others should be endorsed by law (147).

**Improve access to care for people with epilepsy**

On the basis of the specialities in the health system, history and the level of epilepsy management in the different countries, different aspects of

early diagnosis, pharmacotherapeutics, surgery, continuous care and rehabilitation should be stressed.

Even though there are large regional and national variations in the provision of epilepsy care across Europe, it was striking that the same problem areas were reported. The commonest problems were lack of or under-use of epilepsy surgery; lack of comprehensive care, stigma and social problems; the high cost of (especially the newer) antiepileptic drugs; lack of specialists and of specialized epilepsy care; lack of financing, equipment and resource allocation; insufficient professional education and knowledge about epilepsy and lack of epidemiological data. It became clear that, even in the affluent societies of Western Europe, people with epilepsy are not a priority and the organization of their health care is inadequate, as patients are not adequately referred from primary to higher levels of care.

#### **Make epilepsy surgery, which is potentially curative, more widely available**

At the European level, about 6 million people are considered to have active epilepsy (1); 3.3% of this prevalent population represents almost 200 000 persons who might benefit from surgical treatment of their epilepsy.

Surgery programmes should be established in countries that are large enough to make surgery cost-effective. For those countries where it would not be rational to develop independent surgery programmes, regional cooperation would be a possible solution.

#### **Establish more rehabilitation units in epilepsy centres across Europe**

Comprehensive care, in which medical intervention (e.g. antiepileptic drug treatment or epilepsy surgery) is linked to non-medical intervention (e.g. counselling, psychosocial assistance and rehabilitation), is an important part of epilepsy management. Although seizure control is a critical factor affecting social function, managing the consequences on one's daily life is often the most challenging component of epilepsy care.

Coordination of the necessary services and programmes, such as psychological referral, specialized epilepsy centres, outpatient rehabilitation settings, community based programmes and vocational rehabilitation, is best undertaken by multidisciplinary teams. At present in European countries with the lowest availability of comprehensive epilepsy teams, one such team would have responsibility for about 18 000 patients, about 6000 of whom would have pharmacoresistant epilepsy (41). It is imperative that more rehabilitation units should be established in epilepsy centres across Europe.

#### **Promote and reinforce epilepsy research in the region**

Actions intended to meet the needs of epilepsy research in Europe should recognize and promote the existing research groups; no fewer than 132 highly productive groups are active in Europe. It will also be important to define research priorities, including studies of prognostic factors and prevention of the unfavourable evolution of epilepsies, with emphasis on developmental age, epilepsy genes and epileptogenic mechanisms that can be counteracted by new drugs, surgical procedures or social interventions. International multidisciplinary studies combining basic and clinical methods should be conducted to meet the challenges listed above. Collaborative study designs suitable for providing educational opportunities (e.g. young investigator exchange programmes) and for raising the scientific profile throughout Europe should be encouraged. Much could be gained from creating banks of biological material (e.g. brain tissue from surgical specimens, DNA) and data banks, which could make resources available for collaborative international studies. European research investments in the field of epileptology should be increased by coordinating national research granting agencies and promoting interactions and synergies between industrial and academic laboratories.

A recent review on the epidemiology of epilepsy showed that no studies were identified from large areas of Europe, especially from Eastern European (except the Baltic countries) and Eastern

Mediterranean countries (18). Prospective studies in different settings should be strongly encouraged to establish the magnitude of possible geographic differences in incidence; the contribution of different aetiologies and risk factors to geographic variations in incidence. Long-term population based outcome studies of people with specific epileptic syndromes and risk factors and special groups such as children and adolescents and the elderly are urgently warranted. Studies of the incidence of sudden unexpected death in epilepsy (SUDEP) and risk factors in different settings are strongly to be encouraged (see also section 5. Research).

**Stimulate studies of the economic aspects of epilepsy to allow more effective use of limited resources**

Many studies have a bottom-up design, which provides a fairly detailed view of the resource consumption of patients. However, in many cases these studies are limited to patients from one single or a few hospitals, which makes generalization questionable. Another weakness is that the data tend to show the average costs of patients with epilepsy rather than epilepsy-specific costs. Furthermore not all studies include costs for production losses (indirect costs).

Cost data from many parts of Europe especially the CIS and Mediterranean countries are lacking. More cost-of-illness studies on epilepsy are clearly needed. (156).

**Organize educational campaigns about epilepsy for the media and the public, for professionals and for people who have the condition**

Education is needed at multiple levels to reach all those involved in epilepsy management, including the patients themselves.

Patients' organizations should be supported in all possible ways in order to increase public awareness, spread better information about the nature of epilepsy, improve the self-esteem of patients and improve their role in society (1).

Knowledge about differences in the pattern of provision of epilepsy care and about the main problems encountered is helpful in continuing efforts to ensure high-quality management of epilepsy all over Europe. Problems in Europe include the lack of comprehensive care, the lack of epilepsy specialists (including neuropsychologists) and the need for education of medical professionals at community and specialist level.

Further education is in high demand in all the eastern countries, on various levels, including for epilepsy specialists, neurologists, paramedical personnel and the patients themselves and this activity should be supported further.

Epileptology as a speciality, with chairs and comprehensive centres, should be built up in countries where it is not established. The teaching of epilepsy in medial institutions would be improved by this development.

If the above recommendations were followed by actions, epilepsy care will improve significantly. Good information gives people with epilepsy knowledge of their condition. They can then make informed choices, and achieve more personal control and a better quality of life. In addition, education of the professionals concerning management of the condition would enhance appropriate diagnosis and treatment at an early stage, thus limiting the burden of the disorder. ILAE, IBE, WHO and other agencies will work together towards achieving these objectives.

## 9. Annexes

### ■ Annex I. European Declaration on Epilepsy

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At a meeting in Heidelberg, Germany, on 25 October 1998, over 100 leaders of European professional and lay bodies, WHO representatives and health experts from governments and universities unanimously agreed the declaration.

- Six million people in Europe currently have epilepsy. Fifteen million will have epilepsy at some time of their lives
- Epilepsy has profound physical, psychological, and social consequences
- Children, adolescents and the elderly are especially afflicted by non-detection and inadequate treatment.
- With appropriate treatment over three quarters of people with epilepsy could lead normal lives free of seizures
- Epilepsy costs the countries of Europe over 20 billion Euro every year, an amount that could be significantly reduced with effective action.

"We call on the governments of Europe, the European Union, and all health care providers to join us in taking strong and decisive action to meet the objectives of the Global Campaign Against Epilepsy launched by the WHO, ILAE and IBE".

Specifically, we urge action:

- to improve public understanding of epilepsy and thereby reduce its stigma;
- to remove discrimination against people with epilepsy in the workplace;
- to help people with epilepsy to understand their condition and to empower them to seek appropriate treatment and lead fulfilled lives;
- to improve the knowledge of health care professionals and other professionals about epilepsy, before and after graduation;
- to ensure the availability of modern equipment, facilities, trained personnel and the full range of antiepileptic drugs, so that an accurate diagnosis can be made leading to the most effective treatment;
- to encourage research on epilepsy and its management;
- to encourage close liaison among governments, health and social authorities and agencies, and the national chapters of the ILAE and IBE;
- to support the publication of a 'white paper' as a detailed public health statement on epilepsy in Europe;
- to provide practical assistance for countries with underdeveloped epilepsy services within and beyond Europe.

## Annex II. Cabinet Paper



### PAPER TO CABINET

**To:** Cabinet  
**From:** Executive Director, Social Change and Mental Health  
**Date:** 03 December 1999  
**Topic:** GLOBAL CAMPAIGN: BRINGING EPILEPSY OUT OF THE SHADOWS

#### Background

##### a) Impact on health

- Epilepsy is one of the most common serious brain disorders worldwide and it imposes a large economic burden on health care systems. Epilepsy is universal, with no age, racial, social class, national nor geographic boundaries
- There are 40-50 million sufferers in the world today, 85% of whom live in developing countries. An estimated two million new cases occur each year globally. At least 50% of cases begin at childhood or adolescence
- Epilepsy has serious physical, psychological and social consequences. Epilepsy has a significant mortality (four times the expected rate in young adults). There is a hidden burden associated with stigma and discrimination in the community, work place, school and home
- 70 to 80% of people with epilepsy could lead normal lives if properly treated. However, in developing countries 60 to 90% of people with epilepsy receive no treatment due to inadequacies in health care resources and delivery, and due to social stigma.

##### b) Existing activities

In 1997 three international organizations, the World Health Organization (WHO), the International League Against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE) joined forces to initiate a Global Campaign Against Epilepsy (GCAE).

On initial stage the strategy of the campaign was essentially focused on advocacy and awareness activities:

- In 1998 at a meeting in Heidelberg sponsored by the German Government, the European Declaration on Epilepsy was unanimously adopted;
- In 1998 and the first half of 1999, twenty-seven countries have joined or are planning to join the Global Campaign Against Epilepsy.

Experience of initial stage of the campaign created rational for suggestion of a second stage of the GCAE with a new and more ambitious goal: to improve health care services, treatment, prevention, and social acceptance of epilepsy worldwide. A Consultative Meeting on Epilepsy held in WHO/HQ in April 1999 with participation of representatives from IBE, ILAE, WHO Regional Advisers and experts recommended to boost the Campaign and to proceed with demonstration project on epilepsy within the GCAE frame (Meeting Report: MNH/NND/99.3). This project would have to work as part of a country's current health system in order to ensure that epilepsy interventions would be sustainable and able to provide appropriate care over long term including availability of essential antiepileptic drugs.

#### Strategy and Proposal

The strategy of the GCAE includes two parallel and simultaneous tracks: 1) raising of general awareness and understanding of epilepsy, and 2) supporting Departments of Health in identifying needs and promoting education, training, treatment, services, research and prevention nationally.

1. To provide a platform for general awareness on epilepsy, the following is proposed:
  - to intensify and boost the Campaign in the year 2000 with the participation of the Director-General of WHO, WHO Regional Directors and Presidents of relevant NGOs;
  - to announce a Global Awareness Day for Epilepsy;

- to organize regional conferences on public health aspects of epilepsy in the six WHO Regions, including a Declaration on Epilepsy, based on the European model.

2. To assist Departments of Health in the development of national programmes on epilepsy, the following was proposed:

- to provide information and support for national initiatives under the GCAE;
- to initiate demonstration projects in China (WPRO), Honduras (AMRO), Jamaica (AMRO), Panama (AMRO), Senegal (AFRO), and Zimbabwe (AFRO).<sup>2</sup>

The objectives of the demonstration projects are:

- to reduce the treatment gap and the physical and social morbidity of people suffering from epilepsy by intervention at a community level;
- to train and educate health professionals;
- to dispel stigma and promote a positive attitude to people with epilepsy in the community;
- to identify and assess the potential for prevention of epilepsy;
- to develop a model for promotion of epilepsy control worldwide and for its integration in the health systems of participating countries.

Evaluation criteria: Reduction in treatment gap, change in public attitudes, potential for prevention.

Duration: 4 to 5 years.

### **Partners**

Within the framework of the GCAE, WHO has already established a good working relationship with the professional (ILAE) and lay (IBE) NGOs for epilepsy. The Regional Offices of AFRO, EURO and AMRO are actively involved.

Partnerships are being developed among organizations of the United Nations system, nongovernmental organizations, WHO collaborating centres, the private sector, academic and research groups, Foundations and donors.

The following WHO departments have already expressed support: Department of Child and Adolescent Health Development, Department of Resource Mobilization and Office of Press and Public Relations. Contacts are being established with the clusters of Communicable Diseases, Non-Communicable Diseases and Department of Essential Drugs and Other Medicines in the cluster of Health Technology and Pharmaceuticals. A proposal to approach the pharmaceutical industry for financial support was considered by the Committee on Private Sector Collaboration (CPSC). All the neuroscience NGOs including the World Federation of Neurology and the International Child Neurology Association support the Global Campaign Against Epilepsy.

### **Recommendations**

1. In the year 2000 to intensify and boost the GCAE and announce a Global Awareness Day for epilepsy in the presence of the Director-General, Executive Director as well as the Presidents of the participating NGOs. Regional offices will replicate similar high visibility events in all Regions, in the presence of Regional Directors, NGOs and media-attracting personalities.
2. In 2000 initiate the development of demonstration projects as model for the reduction of treatment gap and stigma, improvement in education, training and health care delivery, and promotion of prevention.
3. During the period 2000-2004 hold regional conferences on public health aspects of epilepsy, including a Declaration on Epilepsy as a basis for regional political action.
4. Within the next six months organize a meeting with appropriate United Nations agencies and representatives of the pharmaceutical industry to explore the possibility of furthering collaboration and mobilizing resources for the campaign in accordance with the WHO Guidelines on Interaction with Commercial Enterprises and the aforesaid decision of the CPSC.

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<sup>2</sup> Criteria for country selection in project are: willingness to participate, political contacts, availability of key WHO Collaborating Centre or country representative, IBE/ILAE /other epilepsy organizations, existence of basic primary health care infrastructure, regular and basic AED supply, facility of communication.

## Annex III Organizations

### Lay organizations

In Europe and elsewhere, associations have been founded to meet the specific needs of people affected by epilepsy. The services offered by lay organizations respond to a wide range of social issues associated with the diagnosis. The network of epilepsy associations in Europe is well established. In Europe there are more lay epilepsy organizations than in any other WHO Region (figure 13).

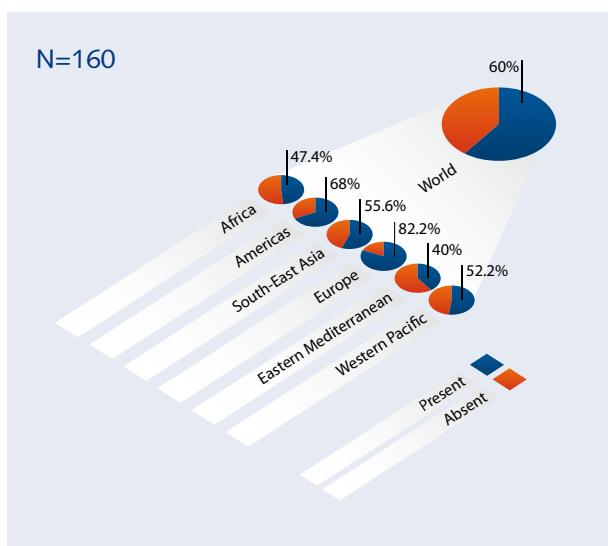


Figure 13: Patient and lay associations for epilepsy in WHO regions and the world (Atlas: Epilepsy Care in the World 2005)

### Types of organization

The structure of a lay epilepsy association can vary considerably in terms of resources, services and membership. At one end of the spectrum are small self-help or support groups. At the other end of the spectrum are large, national organizations offering a significant range of services and support to their many thousands of members. At present, in Europe, there are six or seven such organizations.

Between these two models lie the majority of European organizations offering support to people affected by epilepsy. Some have a national branch network and a limited number of paid staff providing services to members, while in resource poor countries or where an epilepsy association is in its infancy all the work undertaken by the association might be on a voluntary basis. While in some countries there may be only one lay

organization representing people affected by epilepsy, in several others there are a number of organizations offering similar or distinct services.

All lay epilepsy organizations, irrespective of size or location, share a common goal, to improve the lives of persons affected by epilepsy.

### Services provided

For most people with epilepsy in Europe, the problem is not the condition itself but the associated difficulties. For many people with epilepsy, the greatest problems they face are due to the stigma, which is caused by lack of public awareness about the condition.

Most lay epilepsy organizations in Europe address the above issues and provide support for persons with epilepsy, their families and those who care for them from the moment a diagnosis of epilepsy is made. The services provided by lay organizations are limited only by the available funding.

The principal services provided by epilepsy organizations can be loosely categorized as support and advice, education and advocacy. The support activities might include free or low-cost telephone help-lines; the services of specialist epilepsy nurses; counselling by social workers; information on issues such as schooling, employment, driving, pregnancy and insurance; social events and holiday camps; arrangements with insurance companies to provide reasonably priced insurance cover; and provision of devices and aids, including safety pillows and identification bracelets.

In respect to educational activities, epilepsy organizations target two audiences: people with epilepsy and the general public. As the stigma associated with epilepsy can cause more distress than the condition itself, one of the main objectives of all epilepsy organizations is to raise public awareness and knowledge. This is achieved through public information campaigns in schools, places of employment and shopping centres, with information leaflets and posters. Information is also published in interviews and articles in newspapers and magazines and on radio and television. Many epilepsy organizations also organize annual events, such as

an 'Epilepsy Day' or 'Epilepsy Week', with a range of activities aimed at attracting public attention.

To give people with epilepsy comprehensive information on their condition, organizations provide a range of information materials to their members, including newsletters, information booklets and leaflets, videos and DVDs, and most have a well-maintained website.

### **International Bureau for Epilepsy**

IBE was established in 1961 to act as an international umbrella organization for national epilepsy organizations whose primary purpose is to improve the social condition and quality of life of people with epilepsy and those who care for them. IBE also works to disseminate facts about epilepsy, to increase understanding and knowledge and to provide an international and global platform for the representation of epilepsy. A close liaison is maintained with ILAE, which is an organization of medical professionals involved in the medical and scientific aspects of epilepsy. IBE's membership enjoys a healthy growth. In January 2010 IBE had 122 members in 92 countries worldwide. In Europe, IBE has members in the countries shown in table 6. In recent years, IBE has initiated the establishment of regional groupings within its membership, following as far as possible the regional boundaries used by WHO. The purpose of these regional committees is to focus on issues of particular relevance to chapters in those regions. The IBE European Regional Committee is the largest of these groups and has been successful in establishing important initiatives, such as EUCARE, and in promoting international

initiatives, such as the ILAE/IBE/WHO Global Campaign against Epilepsy. Activities carried out under the banner of EUCARE have included the European White Paper on Epilepsy (1) and Call to Action and the Advocates Group (a lobbyist group of Members of the European Parliament in Brussels, Belgium). In addition, the IBE European Regional Committee organizes biennial epilepsy congresses in Europe, which focus on the social issues related to epilepsy. The Committee is managed by a group of five persons drawn from its members and also arranges annual meetings of all members in Europe.

### **European Federation of Neurological Associations**

The European Federation of Neurological Associations (EFNA) brings together European umbrella organizations of neurological patient advocacy groups, to work with the European Federation of Neurological Societies (EFNS) and other interested parties from a related field in a "Partnership for Progress".

EFNA's mission statement is the following:  
The Federation shall engage in any activities, which contribute to the advancement of neurology and related areas with a view to improving the quality of life of people with neurological conditions, their families and carers.

### **Professional organizations**

There are several professional organizations in Europe working on promotion of research, education and epilepsy care. Most are entirely focused on epileptology, while others are general neurological associations working on epilepsy as one of other

Austria	Greece	Portugal
Belgium	Hungary	Romania
Bulgaria (with 1 associate member)	Iceland	Russian Federation
Croatia	Ireland	Scotland (with 2 associate member)
Cyprus	Israel	Serbia
Czech Republic (with 1 associate member)	Italy	Slovakia
Denmark (with 1 associate member)	Lithuania (with 1 associate member)	Slovenia
Estonia	Macedonia, FYR	Spain
Finland	Malta	Sweden
France	Netherlands, the (with 3 associate member)	Switzerland (with 2 associate member)
Georgia	Norway	United Kingdom (with 1 associate member)
Germany (with 1 associate member)	Poland	

Table 6 European countries in which there are members of the International Bureau for Epilepsy

neurological disorders. The most important European organizations are described briefly below.

### **International League Against Epilepsy (ILAE)**

ILAE is the international organization of professionals working in epilepsy care or research. The League is organized in national chapters. In January 2010 ILAE had 103 chapters world wide (table 7). Their main objectives are to encourage research in epilepsy, to promote prevention, diagnosis, treatment, advocacy and care for people with epilepsy, and to improve education and training within epileptology. The League has appointed a special Commission on European Affairs.

ALBANIA	GERMANY	PORUGAL
ARMENIA	GREECE	ROMANIA
AUSTRIA	HUNGARY	RUSSIAN FEDERATION
AZERBAIJAN	IRELAND	SLOVAKIA
BELGIUM	ISRAEL	SLOVENIA
BULGARIA	ITALY	SPAIN
CROATIA	KAZAKHSTAN	SWEDEN
CYPRUS	KYRGYSTAN	SWITZERLAND
CZECH REPUBLIC	LATVIA	THE NETHERLANDS
DENMARK	LITHUANIA	TURKEY
ESTONIA	MACEDONIA,FYR	UK
FINLAND	MALTA	UKRAINIA
FRANCE	NORWAY	FORMER REP. YUGOSLAVIA
GEORGIA	POLAND	

*Table 7: European countries in which there are chapters of the International League Against Epilepsy*

The mission of the Commission is to stimulate and coordinate all aspects of epileptology across Europe, including the organization of the European congresses on epileptology. One important task is to improve the scientific content of these congresses, evaluated by a sub-commission on congress evaluation. A sub-commission on bursaries stimulates participation from young scientists and clinicians, especially in central and eastern Europe.

The Sub-commission on Central and Eastern Europe facilitates education, quality care and research. The initial task of the Working Group on Development of Quality of Care is to contact national European ILAE chapters and enquire about the availability or need of tertiary care centres, to evaluate the responses,

to consult with relevant third parties and to develop a project for establishing a model tertiary care epilepsy centre or unit in an underserved European country or region. The Commission has now several working groups aiming at various goals and is heavily involved in residential teaching courses in collaboration with EUREPA.

The Commission on European Affairs is heading the 'European Triangle', with the European Advisory Council and EUREPA, acting in close collaboration. The European Advisory Council is an association representing all the European chapters of ILAE, with a Chair and Secretary as executives, exploring the needs for educational programmes and more professional collaboration within Europe. The Chair and Secretary are members of the Commission on European Affairs.

EUREPA has been responsible for educational activities within the Commission on European Affairs and had its own Executive and Advisory Board. EUREPA arranged educational courses at international and European epilepsy congresses and at some neurology congresses.

### **European Federation of Neurological Societies (EFNS)**

EFNS is an organization for neurologists across Europe. All national neurological societies (i.e. professional and scientific organizations) in Europe that are affiliated to the World Federation of Neurology are registered members of the EFNS.

The role of EFNS is to advance the development of neurological sciences throughout Europe; to stimulate, encourage and help develop European programmes of clinical and experimental neurological research and teaching; to promote international exchange arrangements for neurologists and neuroscientists, especially those in training; and to handle current political issues in neurology on behalf of its members.

### **European Neurological Society (ENS)**

The European Neurological Society, like EFNS, is devoted to the advancement of neurological research in Europe. Unlike EFNS, it is an organization consisting of individual European neurologists and neuroscientists rather than associations or societies.

### **European Paediatric Neurology Society (EPNS)**

EPNS is a society of paediatric neurologists and members of allied disciplines from all parts of Europe dedicated to promoting clinical care and scientific research in the field of paediatric neurology. Paediatric Neurologists, and colleagues in related fields, from as many European countries as possible, are encouraged to participate in the activities of the EPNS.

### **World Health Organization (WHO)**

The Constitution of the World Health Organization (WHO) came into force on 7 April 1948 - a date which is now celebrated every year as World Health Day. WHO is the specialist health agency within the United Nations system. It is responsible for providing leadership on global health matters, shaping the health research agenda, setting norms and standards, articulating evidence-based policy options, providing technical support to countries and monitoring and assessing health trends.

WHO's objective, as set out in its Constitution, is the attainment by all peoples of the highest possible level of health. The Constitution defines health as a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.

WHO has 193 Member States, 53 of which are situated in Europe.

The work of the WHO European Mental Health programme is clearly outlined in the Helsinki Action

Plan endorsed by ministers of health in the WHO European Region. In accordance with each country's needs and resources, the challenges over the next five to ten years are to develop, implement and evaluate policies and legislation that will deliver mental health activities capable of improving the well-being of the whole population, preventing mental health problems and enhancing the inclusion and functioning of people experiencing mental health problems. The priorities for the next decade are to:

- foster awareness of the importance of mental well-being
- collectively tackle stigma, discrimination and inequality, and empower and support people with mental health problems and their families to be actively engaged in this process
- design and implement comprehensive, integrated and efficient mental health systems that cover promotion, prevention, treatment and rehabilitation, care and recovery
- address the need for a competent workforce, effective in all these areas
- recognize the experience and knowledge of service users and carers as an important basis for planning and developing services.

In accordance with these five priorities, the mental health programme is actively looking to cooperate with agencies to combat epilepsy. The programme can support mechanisms to involve more European Member States and their partners in activities to combat stigma, restore dignity and reduce the treatment gap for people with epilepsy. It can promote dialogue with governments, consumer associations, nongovernmental organizations, academic institutions and development partners to address the problem and offer appropriate recommendations.

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<sup>3</sup> The term "carer" is used here to describe a family member, friend or other informal care-giver.

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## 7. Further information

### ■ Further information on the Global Campaign against Epilepsy can be obtained from:

#### **International Bureau for Epilepsy**

Key contact: Mike Glynn  
Brainwave The Irish Epilepsy Association  
249 Crumlin Road  
Dublin 12  
Ireland  
Email: [mikeglynn@epilepsy.ie](mailto:mikeglynn@epilepsy.ie)

#### **International League Against Epilepsy**

Key contact: Solomon L. Moshé  
Albert Einstein College of Medicine, Montefiore Medical Center, Department of Neurology  
1410 Pelham Parkway So, K316  
Bronx, NY 10461  
USA  
E-mail: [moshe@aecon.yu.edu](mailto:moshe@aecon.yu.edu) [moshe@aecon.yu.edu](mailto:moshe@aecon.yu.edu)

#### **Campaign Secretariat**

Key contact : Hanneke M. de Boer  
Stichting Epilepsie Instellingen Nederland  
Achterweg 5  
2103 SW Heemstede, Netherlands  
Tel: + 31 23 55 88 412  
Fax: + 31 23 55 88 409  
Email: [hdboer@sein.nl](mailto:hdboer@sein.nl)

#### **World Health Organization**

Key contact: Dr Shekhar Saxena  
Department of Mental Health and Substance Abuse  
20 Avenue Appia  
1211 Geneva 27  
Switzerland  
Tel: + 41 22 791 3625  
Fax: + 41 22 791 4160  
Email: [saxenas@who.int](mailto:saxenas@who.int)

#### **AFRO**

Mrs Carina Ferreira-Borges  
Technical Officer DNC/MNH  
World Health Organization  
Regional Office for Africa  
Boîte postale 6  
Brazzaville  
Congo  
Email: [ferreiraborgesc@afro.who.int](mailto:ferreiraborgesc@afro.who.int)

#### **AMRO**

Dr Jorge Jacinto Rodriguez  
Unit Chief  
Mental Health, Substance Abuse, and Rehabilitation  
Technology and Health Services Delivery (THS)  
Regional Office for the Americas/Pan American Sanitary Bureau  
World Health Organization  
525, 23rd Street, NW

Washington, DC 20037

USA

Email: [rodrigjo@paho.org](mailto:rodrigjo@paho.org)

#### **EMRO**

Dr Khalid Saeed  
Regional Advisor, Mental Health and Substance Abuse  
World Health Organization  
Regional Office for the Eastern Mediterranean  
Abdul Razzak Al-Sanhouri St.  
P.O. Box 7608  
Naser City 11371  
Cairo  
Egypt  
Email: [saeedk@emro.who.int](mailto:saeedk@emro.who.int)

#### **EURO**

Dr Matthijs Muijen  
Regional Advisor, Mental Health  
Regional Office for Europe  
World Health Organization  
8 Scherfigsvej  
DK-2100 Copenhagen  
Denmark  
Email: [muijenm@who.int](mailto:muijenm@who.int)

#### **SEARO**

Dr Vijay Chandra  
Regional Advisor, Mental Health and Substance Abuse  
Regional Office for South-East Asia  
World Health Organization  
World Health House  
Indraprastha Estate  
Mahatma Gandhi Road  
New Delhi 110002  
India  
Email: [chandrv@searo.who.int](mailto:chandrv@searo.who.int)

**WPRO**

Dr WANG Xiangdong

Regional Adviser in Mental Health and Control of Substance

Abuse

World Health Organization

Regional Office for the Western Pacific

P.O. Box 2932 (1099 Manila)

United Nations Avenue

1000 Manila

Philippines

Email: wangx@wpro.who.int