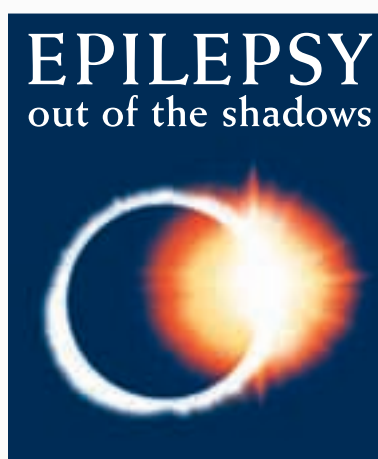


# **EPILEPSY IN THE WHO AFRICAN REGION:**

## **Bridging the Gap**



**The Global Campaign Against Epilepsy  
“Out of the Shadows”**

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# Foreword

Epilepsy is responsible for an enormous amount of suffering. On the African continent it affects 10.000.000 people directly. They are of all ages, but especially within childhood, adolescence and the ageing population.

Epilepsy provides the clearest example of a neurological disorder for which effective and cost-efficient treatment is available. Recent studies both in the developing and in the developed world revealed that if properly treated up to 70% of people with this condition could live productive and fulfilling lives, free from seizures.

Yet in developing countries up to 90% of the people who have this condition, and sometimes even more, are excluded from care and consequently remain in the shadow of this treatment gap.

One of the reasons for this is that in many parts of the world there is a grave social stigma attached to epilepsy. People believe that epilepsy is contagious and hesitate to help or touch the person who has fallen during a seizure. The stigma of epilepsy also has a great influence on the education of children and young people.

The solutions to these problems are too complex to be solved by individual organizations. Therefore the three most important international organizations working in epilepsy – the International League against Epilepsy, the professional organization in the field of epilepsy, the International Bureau for Epilepsy, the lay organization, and WHO – have joined forces in the ILAE/IBE/WHO Global Campaign against Epilepsy in order to bring epilepsy “out of the shadows”.

The Campaign will assist Governments worldwide to make sure that diagnosis, treatment, prevention and social acceptability are improved.

The strategy involves two parallel tracks:

- raising general awareness and understanding of epilepsy;
- supporting national Departments of Health in identifying needs and in promoting education, training, treatment, services, research and prevention nation-wide.

The tactics are:

1. To generate regional declarations on epilepsy:
  - producing regional reports and other relevant materials;
  - incorporating epilepsy care in National Health Plans;
  - facilitating the establishment of national organizations of professionals and of lay persons who are dedicated to promoting the well being of people with epilepsy.
2. To help organize demonstration projects that will illustrate good practice in the provision of epilepsy care. External funds will be used to initiate the demonstration projects, but will not be used to provide services or medication in the long term, as the aim is to demonstrate that epilepsy care should be locally sustainable.

The Campaign has been officially launched and activities are taking place in about 50% of AFRO countries.

It is evident that the collaboration between IBE, ILAE and WHO has given the Campaign the opportunity to build a framework for concerted action on a global, regional and national level to raise awareness and diminish the treatment gap. Partnerships between WHO and NGOs are clearly the way forward to bring epilepsy “out of the shadows”, as is shown by the situation in Africa.

Dr. Ebrahim Malick Samba  
*WHO Regional Director for Africa*

## Preface

Epilepsy is one of the major brain disorders worldwide and should be considered a health care priority in Africa. It is triggered by abnormal electrical activity in the brain resulting in an involuntary change in body movement, function, sensation, awareness and behaviour. The condition is characterized by repeated seizures or “fits” as they are commonly called. These take many forms ranging from the shortest lapse of attention to severe and frequent convulsions.

WHO estimates that of the 10 million people in Africa who live with epilepsy, 80% or eight million are not treated with readily available modern drugs, the cheapest of which cost about US\$ 5.00 per patient per year. Indeed, thanks to modern medicine, most of the causes of symptomatic epilepsy in our region can be greatly reduced by prevention and treatment.

Yet, epilepsy continues to take its toll among our people causing impaired physical, psychological and social functioning of those affected, and equally serious psychological, social and economic consequences for their families.

Worse still, people with epilepsy, sometimes along with their family members, are often stigmatized. This stigmatization generates a hidden burden, which discourages patients from seeking the diagnosis and care they need and deserve. Another fallout of stigmatization is the discrimination, as people who experience seizures but are able to work are unemployed; and many who are able to find employment are underemployed.

The present report introduces both the lay reader and the professional to epilepsy, which affects more than 50 million people worldwide, thus making this medical condition an important public health problem.

It chronicles the involvement of the WHO Regional Office for Africa in milestones such as the May 2000 Dakar African Declaration on Epilepsy as a health care priority in Africa, the participation at the Launch of the Second Phase of the ILAE/IBE/WHO Global Campaign Against Epilepsy in Geneva in

February 2001, the two intercountry meetings on the Global Campaign Against Epilepsy (GCAE), in June 2001 in Harare for Anglophone countries and March 2002 for Francophone countries, as well as the inclusion of epilepsy as part of the “African Exhibition on Poverty and Health: Challenges for Development”.

The launch of the Campaign in some countries of the Region indicates Government’s commitment in helping people with epilepsy to overcome the struggle against stigma and discrimination.

The report “Epilepsy in the African Region: Bridging the Gap” also provides a panoramic view of the epilepsy situation in the Region, outlines the initiatives taken by WHO and other partners to address the problem, defines the current challenges and offers appropriate recommendations.

There is much to be learnt from this report. It will serve as a potent advocacy tool for taking epilepsy “**out of the shadows**” in the African Region.

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# Abbreviations

AED: Anti Epileptic Drug	HQ: Head Quarters, Geneva
AIDS: Acquired Immuno-Deficiency Syndrome	IBE: International Bureau for Epilepsy
AFRO: Regional Office for Africa	ILAE: International League Against Epilepsy
AMRO/PAHO: Regional Office for the Americas	MD: Doctor of Medicine
BZD: Benzodiazepine	MNH: Mental Health
CBZ : Carbamazepine	MRI: Magnetic Resonance Imaging
CNS: Central Nervous System	PB: Phenobarbital
CT: Computerised Tomography Scanner	PHT: Phenytoin
DDD: Defined Daily Dose	PWE: People with epilepsy
DNC: Division of Non-Communicable Diseases	SEARO: Regional Office for South-East Asia
DP: Demonstration Project	UN: United Nations
EEG: Electroencephalogram	UNDP: United Nations Development Program
EMRO: Regional Office for the Eastern Mediterranean	US\$: United States Dollars
EURO: Regional Office for Europe	VPA: Valproate
GCAE: Global Campaign Against Epilepsy	WB: World Bank
GNP: Gross National Product	WHO: World Health Organization
GDP: Gross Domestic Product	WPRO: Regional Office for the Western Pacific
HIV: Human Immuno-deficiency Virus	





# 1. Introduction

Epilepsy is one of the most common and serious brain disorders in the world. It affects at least 50 million people in the world. About 100 million people will have at least one epileptic seizure at some time in their lives. Most of the causes of symptomatic epilepsy are preventable and treatable. The condition has serious physical, psychological, social and economic consequences for the concerned persons and their families. In spite of global advances in diagnosis and treatment in recent years, about eight million people with epilepsy in Africa are not treated with modern anti-epileptic drugs. Epilepsy is a treatable condition and relatively cheap medication is available, however the treatment gap in developing countries remains very high.

The Global Campaign Against Epilepsy (GCAE) is a joint effort of the International Bureau for Epilepsy (IBE), the International League Against Epilepsy (ILAE) and the World Health Organization (WHO). With the theme *“Epilepsy Out of the Shadows”*, the Global Campaign aims to support countries worldwide in reducing the burden caused by epilepsy through the improvement of acceptability, access to services, prevention and quality care.

Campaign activities in the region include: consultative meetings on the implementation of the Global Campaign Against Epilepsy in the African Region; the inclusion of epilepsy as part of the African Exhibition on *“Poverty and Health: Challenges for Development”*; the launch of the Campaign in more countries; the initiation of demonstration projects and the gathering of information on resources for the management of epilepsy through a WHO/ILAE/IBE questionnaire on country resources for epilepsy.<sup>1</sup>

By assessing the progress made on the implementation of the Campaign *“Epilepsy, Out of the Shadows”* in the African Region, this document draws a *“picture”* of the present situation and explores mechanisms to involve more Member States and their partners in activities to combat

stigma, restore dignity and reduce the treatment gap for people with epilepsy. It is an advocacy tool and an instrument for dialogue with governments, consumer associations, nongovernmental organizations, academic institutions and development partners.

<sup>1</sup> The questionnaire can be obtained from the Campaign Secretariat, Achterweg 5, 2103 SW Heemstede, The Netherlands

## 2. General background on the African Region

Countries involved in Campaign activities



Epilepsy is not only a medical condition, it also includes sociological, economical and cultural dimensions. Secondary causes of symptomatic epilepsy in Africa are mainly related to the cerebral complications of endemic parasitic and infectious diseases, to head trauma and to the poor perinatal care for both the mother and the child. Poverty and unsafe environment play an important role as determinant factors. The levels of education, the communication network, the availability of resources within the health care system, among others, have a major influence on the management of the epilepsy-related burden. Thus, epilepsy in Africa has to be seen in a public health perspective.

### 2.1 Population

The African Region of WHO is composed of 46 countries<sup>2</sup> with a total population of 639 631 000 people.<sup>3</sup> With a current actual population growth of 2.8 %, it is projected that by 2015 this will decline to 2.4%. General characteristics of the population in the African Region include: an age distribution in favour of youth<sup>4</sup>, predominance of poverty, and a majority of people living in rural areas. About 36% of Africans live in cities. Most of these live in the suburbs in poor conditions characterized by overcrowding, poor water supply and bad

sanitation<sup>5</sup>. Consequently there is a high prevalence of communicable diseases such as malaria, meningitis, cysticercosis and tuberculosis, which are frequent causes of epilepsy.

The mean general under-five mortality rate was 223 deaths per 1000 live births in the 1970s. Currently, it is 174 deaths per 1000 live births in sub-Saharan Africa<sup>6</sup>. The infant mortality rate reflects the adverse perinatal environment that favours the development of secondary epilepsy. The life expectancy at birth ranges from 37 to 68 years for males, and 38 to 74 years for females.<sup>7</sup> In some countries, because of different factors, including the HIV/AIDS pandemic, life expectancy has decreased to 40 years or even below, thus impacting negatively on the socioeconomic development. With infection rates ranging from 15% to 38.8%, HIV/AIDS is a major challenge in the countries of the African Region. Women represent on average 50.3% of the population and pay a heavy price to pregnancy and life giving: from 1990 to 1997, the mean ratio of maternal deaths has been 664 per 100 000 births. The mean rate of births attended by skilled health staff in sub-Saharan African countries range from 10% in Ethiopia<sup>8</sup> to 100% in Mauritius.

### 2.2 Economy

Sub-Saharan Africa includes 11% of the world population, but benefits from only 1.3% of the income. The UNDP Human Development Indicator reveals that in 2001 the mean Gross Domestic Product per capita in the sub-Saharan countries was US\$ 1.690, ranging from US\$ 12.508 (Seychelles) to US\$ 490. (Sierra Leone), compared to a mean GDP per capita of US\$ 24.973 in the developed world. Of the 40 least wealthy countries in the world, 32 (80%) are in Africa. In the poorest countries of the African region, 61 to 72.8% of the population live on less than US\$ 1.00 per day (UNDP, 2001).

<sup>2</sup> 20 English speaking, 20 French speaking, 5 Portuguese speaking and one Spanish speaking.

<sup>3</sup> WHO, 2001 and UNDP, 2001

<sup>4</sup> The age distribution reveals that people aged from 0 to 14 represent 43.4% of the general population. Those who are more than 65 represent 3.1 %.

<sup>5</sup> World Bank 1999.

<sup>6</sup> UNDP, 2001

<sup>7</sup> WHO, 2001

<sup>8</sup> UNDP, 2001

When drawing policies and strategies for epilepsy management in the countries of the Region there is a compelling reason to consider using phenobarbital, as it is the cheapest anti-epileptic drug costing with a median cost of US\$ 6.00 per patient per treatment year.

## ■ 2.3 Education and communication networks

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The mean adult illiteracy rate in the African Region is about 38.5%, but it is higher among females. Regarding the international standard, which is rated from best (1.0) to worst (0.1), the mean education index in the developed world is 0.90 in contrast to 0.55 in Africa. The average number of years of schooling is 7.6 for males and 6.7 for females. The rate of illiteracy is an important factor to consider and explains why it is important to utilize, radio (available to 158 per 1000 in 1996), and/or television (56 sets per 1000 people in 1997) in order for awareness raising to be efficient.<sup>9</sup> These two means which are closer to the verbal traditions of the largest part of the population, should use local languages to reach people better. Only 13.8 copies of daily newspapers per 1000 people were available in 1996. They are mainly written in French, English, Spanish, Arabic and Portuguese. The number of telephone lines in the whole of sub-Saharan Africa is less than in Manhattan (New York City). There is a need to increase awareness concerning the potential benefits of the use of information technology including tele-medicine for health management and research in general.

## ■ 2.4. Health

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### ■ 2.4.1 General health conditions

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The most prevalent disorders in terms of morbidity and mortality for people living in the Region are infections, perinatal and nutritional factors (155 682 000 cases; 4 597 000 deaths out of the 6 327 000 reported). These are followed by noncommunicable disorders: cardiovascular disease,

cancer, endocrine and neuro-psychiatric disorders, including epilepsy, other anatomical system disorders and injuries (36 552 000 cases; 1 043 000 deaths out of the 6 327 000 reported).

Perinatal conditions are the leading factors causing disability including epilepsy and other neuro-psychiatric and developmental disorders. Of under-5 children in low-income sub-Saharan African countries, 10 to 57% are underweight and/or height. The lowest percentage of children who are underweight are found in Seychelles and Mauritius (5 to 6%). This phenomenon is correlated with the prevalence of anaemia in pregnant African women, which was 40 % in years 1985 to 1995 (World Bank, 1999). The mean rate of child immunization has dramatically improved since 1980 in several areas, but the median average in the African Region shows that only 30 to 45% are fully immunized against tuberculosis and measles (UNDP, 2001). On average only 61% (range 24–100) of inhabitants in the WHO/AFRO region have access to safe water and 47% (range 13–99) to sanitation. These extreme conditions facilitate transmission of parasitic and bacterial infections, some of which have a predilection for the central nervous system and may be epileptogenic.

Health financing in sub-Saharan Africa is extremely underfunded. The mean expenditure per capita (including public and private) is US\$ 40, ranging from US\$ 4.00 to US\$ 230.00 (in South Africa). 30 countries out of 46 spend less than US\$ 25.00 per capita per year. The ratio of health expenditure as a percentage of GDP ranges from 2.1% to 7.5% (see Country Data from the African Region, Annex 8.3).

### ■ 2.4.2 Health services, care and personnel

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The low medical doctor/population ratio and the scarcity of diagnostic means in the African Region mean that every single human resource should be utilized to bridge the health (general or specialized) management gap. The mean ratio is 61 (range 3–336) nurses and midwives per 100 000 people (information available for 28 countries). The mean ratio of doctors (MD), excluding dentists and clinical officers, is 18 (range 2–132) physicians for

<sup>9</sup> World Bank, 1999

100 000 inhabitants in sub-Saharan Africa, (Table 1)\*. The ratio is much higher in urban than in rural areas. Currently, many African countries do not have sufficient qualified staff in the neurosciences (neurologists, neurosurgeons, psychiatrists) (Table 4). Except for South Africa, the mean ratios for countries which have these medical specialists are: 1 neurologist for one million to 2.8 million people (versus 4/100 000 in Europe); one psychiatrist for 900 000 people (versus 9/100 000 in Europe); and one neurosurgeon for two to six million people (versus 1/100 000 in Europe). Most of the neurosciences services are located in the capitals where the professionals are also often lecturers at the Medical Schools. Any neurology patient who is referred has to travel long distances for a doctor's consultation or investigation in the main city.

#### ■ 2.4.3 Drug policy and control

In order to address the gradual decline in the provision of health care services due to the economic hardships experienced by the Member States of the African Region, a Resolution has been adopted, with the goal to revitalise district health systems through the establishment of a community-based management of essential drugs. Phenobarbital, as an anti-epileptic drug, is on that list. This cheap and once-a-day drug should be more available at a primary level, its use better explained and it should be prescribed more often. Many African countries have implemented the *Bamako Initiative* (see Box 1). Fifteen years later much progress has been made, but much remains to be done. Its expansion is confronted by operational problems caused by poverty, lack of human resources, demographic pressure, the sociocultural context and recurrent emergency situations. The next planned step is to include a larger number of drugs, particularly those that are in generic form, together with a sustainable and efficient quality control. There is a need to strengthen partnerships between public and private sectors to expand health and drug coverage. It is also recommended to link the *Bamako Initiative* with others in the health sector via a sector-wide approach.

\* Table 1, page 33

### Box 1: The Bamako Initiative

*This initiative was set up by Member States of the African Region in 1987 (Regional Committee AFR/RC37/R6). Its main aims are:*

- *To encourage social mobilization initiatives to promote community participation in policies on essential drugs and child health at district level;*
- *to ensure the regular supply of essential drugs of good quality and at lowest cost;*
- *to support the implementation of primary health care;*
- *to define and implement a primary health care self-funding mechanism at district level, especially by setting up a revolving fund for essential drugs.*

*It has often been an important part of the health sector reforms, promoting a minimum package of activities and the availability and affordability of essential drugs with cost-sharing and the effective participation of the population.*

### Box 2: Definition of epilepsy

*Epilepsy refers to a group of chronic brain conditions characterized by recurrent epileptic seizures. Epileptic seizures are the clinical manifestations (signs and symptoms) of excessive and/or hyper-synchronous, usually self-limited, abnormal activity of neurones in the brain. Epileptic seizures represent the most common positive signs and symptoms of brain disturbance. All epileptic seizures, however, are not epilepsy, which requires recurrent epileptic seizures in absence of acute pathology. An individual has a one in ten chance of experiencing at least one epileptic seizure in his/her life. Active epilepsy has been defined as epilepsy that has caused two or more unprovoked seizures on different days in the year prior to the assessment date.*

## 3. Epilepsy in the African Region

### 3.1 Global perspective

The situation of epilepsy in the AFRO region reflects a worldwide prevalence which is remarkably uniform, although the incidence increases in Latin America, the Eastern Mediterranean, South-east Asia and in Africa, with more predisposing cerebral disorders such as communicable diseases, perinatal insults and other brain stressing factors (Reynolds, 2002). About 10% of the whole world population living a normal life span can expect to have at least one epileptic seizure (Engel, 2002). At least 50 million will have recurrent seizures. This could be underestimated, as partial seizures are often not recognized as such in the developing world. Out of the 50 million, 40 million receive no treatment when, for only a small amount of money, 70% of these could lead seizure-free lives.

### 3.2 Epidemiology, diagnosis, aetiology, and outcome

One of the most challenging public health problems in Africa is data collection. Osuntokun et al. (1987) used an instrument developed for WHO by Schoenberg et al. Recently at the University of Limoges, a questionnaire in French has been developed for the assessment of epilepsy prevalence in tropical countries (Preux, 2000). There is not a standard way of collecting data and this situation introduces many biases. Many hospital records do exist but they have not been published. Research on epilepsy epidemiology, using various protocols, has been conducted in many countries in the general population (rural and urban). The questions that are not totally answered are: how reliable are the epidemiological figures? Are they for all epilepsies or just for generalized convulsive seizures?

#### 3.2.1 Incidence

In all developing countries, and particularly in the African region, a very large number of new onset seizures are a consequence of poor perinatal

\* Table 2, page 34

\*\* Table 3, page 35

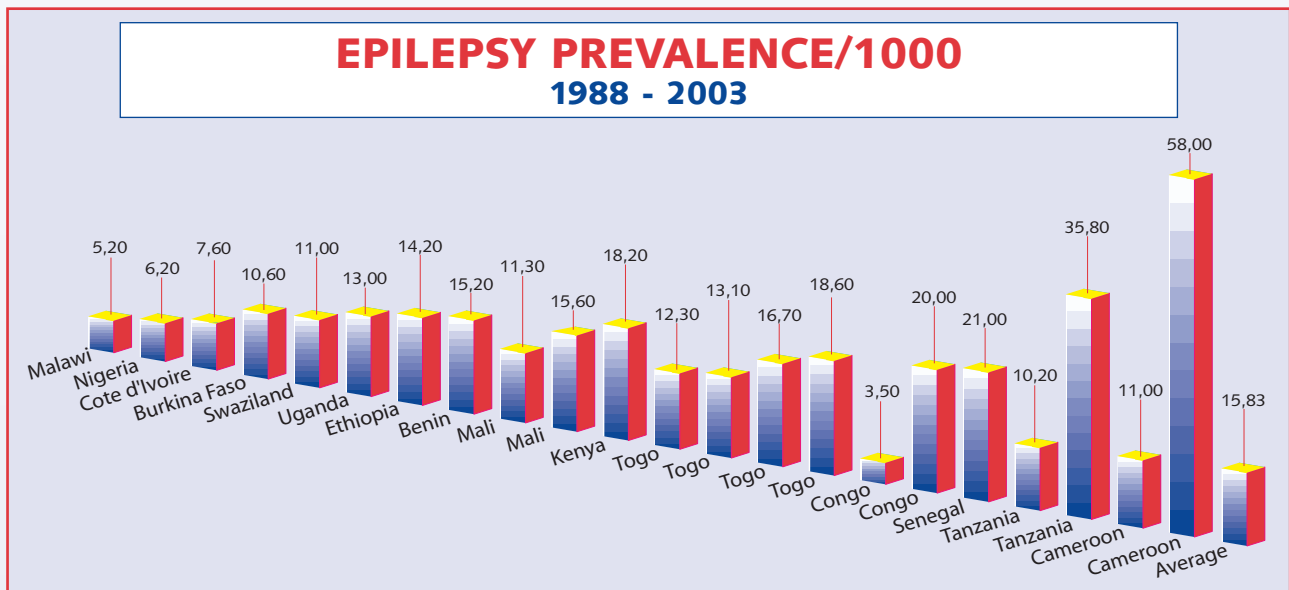
management, the high impact of infectious diseases, and head trauma. Many are preventable conditions (see aetiology). Five controlled incidence studies have been conducted in African countries (Table 2)\*. The number of new cases of epilepsy detected among 100 000 people during one year were: 83 in Burkina Faso, 64 in Ethiopia, 73 in Tanzania, 119 in Togo, and 156 in Uganda. These incidence rates are higher than those reported from the developed world, which usually range from 40 to 70 per 100 000. Neurologists in the African region when interviewed usually report that epilepsy is the second or third reason for consultation, after headaches or peripheral neuropathies, and the second or third reason for hospitalization after strokes and/or spinal cord pathologies (Ndiaye, 2000; Tekle-Haimanot et al, 1997). As in most other places in the world, the highest age-specific incidence occurs from 0 to 20 years: 0–9 years first, then 10–19 years (Hauser, 1995). In a series of 912 Kenyan people, the authors confirmed that the first two decades witness the greatest number of patients (68.5 %), with a sex ratio of 1.8 (Ruberti, 1985). In Ghana, children with convulsive disorder made up 3 % of new patients seen in the paediatric department over a ten-year period. 51.5 % of children consecutively enrolled in a paediatric neuro-developmental clinic of a teaching hospital in Ghana were also suffering from seizures (Commey, 1995). In Algeria, an unpublished report revealed an incidence rate of 56/100 000 (Mait-Kaci, 1978). After young people, the age group most affected by an increased epilepsy incidence is that over 50 years of age, such as reported in Senegal (Martini, 1981).

#### 3.2.2 Prevalence

The main data are indicated in table 3\*\*. If we consider studies performed on population sizes up to 1000, prevalence rates of epilepsy in the African region range from 2.2 to 58 per 1000. One may be cautious about reports based on population study sizes under 1000 as these can lead to very high prevalence rates (Table 3; Druet-Cabanac, 2002). The lowest rate is reported from South Africa (2.2‰). Highest rates of over 15‰ (note: according

to table 2 the median prevalence rate in the AFRO region is about 11%) are mainly detected in rural populations. They reflect poor health conditions resulting in several public health-related diseases complicated by epileptogenic changes in the brain. These are mainly detected in rural populations, raising *de facto* the incidence rates.

epilepsy progresses with a co-morbid psychiatric disorder such as in severe epileptogenic encephalopathies. Up to 80% of epilepsy cases can be diagnosed and successfully managed at primary and secondary levels of healthcare by raising the competence of the personnel in a public health approach (see Box 3). The benefits and cost effectiveness of strengthening the ability of primary



Adapted from table 5

### 3.2.3 Diagnosis

The most important way of diagnosing epileptic seizures worldwide is through interviews and by the usual clinical examination looking for signs and symptoms of disturbed cerebral functions and for evidence of infections that are known to be associated with epilepsy. This can be realised in any health structure (see Boxes 2 and 3). Very often information comes from the relatives who witnessed the event and can describe whether it was accompanied by a loss of consciousness. The majority of reported cases are generalized tonic-clonic seizures that are more spectacular and easier to diagnose. In a thesis by Druet-Cabanac (2002), these are reported in proportion ranging from 12 to 92% of seizures. Accurate data are difficult to obtain from the literature. Roughly 60% of epilepsies appear to be accompanied by convulsive seizures (Loiseau et al, 1991). In the developing countries, patients often wait a long time before consulting a medical centre, particularly when

\* Table 4, page 36

health workers (by training and simple education programmes) in African rural area health clinics to identify and initiate treatment in patients suffering from epilepsy have been demonstrated (Adamolekun et al, 1999). Resistant cases and specific epileptic syndromes should be referred to the tertiary level. It is at the tertiary level that modern neurosciences diagnostic means are utilized to confirm the diagnosis and search for a possible aetiology. In the African Region, with the exception of South Africa and Algeria, the specialized diagnostic tools for brain disorders, necessary for such purposes consist of 79 EEG machines (plus 60 in South Africa and 50 in Algeria), 65 CT-Scanners (plus 214 in South Africa and 30 in Algeria), and 9 MRI's (plus 46 in South Africa and 6 in Algeria). (Table 4)\*. The problem with these equipments is that they are very often badly maintained or out of order. Another issue is the high cost for the patient referred to capital city hospitals. Most of the patients cannot afford the price and therefore cannot benefit from this technological progress.

### Box 3: Diagnosing epileptic seizures

**At the primary and secondary health levels** the best way to diagnose an epileptic seizure is to witness it. But this is rare. Usually a good interview and interpretation of the chronological process leads to a very strong suspicion. Questions should be posed to the patient if possible about the circumstances, pre- and post-ictal, precipitating factors e.g. sleep deprivation, alcohol, etc.. Accompanying persons also should be questioned about what they have seen, done and know about the patient (habit, antecedents, drugs, family, etc). The clinical examination is normal in most of the cases, except for the eventual physical consequences of the seizure (tongue biting, loss of urine, injury) or head trauma.

**At the tertiary health level**, most epilepsies can be managed by any MD. The same approach as the one described above is valuable. One can search for the morphotypes related to epileptic syndromes, examine the eyes, the skin and nervous system. When they are available and financially accessible, and cost-effective, some selected complementary diagnostic procedures can be envisaged. The EEG, depending on technique and methodology, shows abnormalities in 35% to 80%. Laboratory investigations are mainly asked for exploring the aetiology. CT-Scan may be of interest to verify certain hypotheses because it gives an overview of the brain. But in the majority of African contexts only X-ray of the head is available and can, in very few cases, reveal calcifications or alterations suggesting an intracranial expansive process or infections with neurocysticercosis or tuberculosis.

**In specialized centres**, the previous approaches remain valuable. Severe cases could benefit from sophisticated procedures. Lumbar puncture can be realised in case of suspicion of encephalitis and/or meningitis. In a few specialized centres, if indicated after a CT Scan, there may be a need for Magnetic Resonance Imaging or other complementary techniques in very resistant epilepsy in order to detect or confirm the presence of small brain anomalies in the process of localising an epileptogenic focus in a candidate for surgery.

**But, wherever the patient is seen**, one has to be very cautious about cost effectiveness of diagnostic practices.

#### 3.2.4 The aetiologies of epilepsy in the African Region



Onset of epilepsy is highest in childhood but many causes are preventable

The many aetiological factors mean that epilepsy is to be considered an important public health problem in Africa (see Box 5). The prevalence of symptomatic epilepsy is higher than in developed countries (see Box 4). Although in low-income developing countries, many of these factors are

preventable. The prevalence and incidence rates of epilepsy in rural and sub-urban areas are usually higher than in cities. This is due to the fact that risk factors are more concentrated in the rural and the suburban areas where migrants from village to city reside in very poor conditions (Matuja, 1989).

For infants the sequels of birth injury, often after a difficult pregnancy or labour, could lead to epilepsy. Hypoxia and hypoglycaemia are often cited. In children (the most exposed population to epilepsy), febrile convulsions are reported in every African health structure as a major cause of seizures (Rachman, 1970). From Africa there are no data for how often febrile convulsions will continue as partial epilepsy. Prevalent causes of fever are similar in every country and include malaria, bronchopneumonia, upper respiratory tract disorders and measles. Other infections may directly affect the brain and cause epilepsy. These include meningitis, encephalitis and septicaemia (Iloeje, 1991; Izuora and Azubuike, 1977). At all ages, infections remain a constant cause of symptomatic brain stress and seizures (Asindi et al, 1995). The severity is reinforced by malnutrition and poor basic health and economic conditions (Obi et al, 1994; Commey, 1995; Leary et al, 1999).

In the entire African region, all the endemic causes of infection in adults have the potential to involve the brain (Dada, 1970). HIV, encephalitis, and many other viral, bacterial and parasitic diseases, if poorly managed or neglected, can lead to epilepsy. Many authors have reported high prevalence rates of cysticercosis infection among people with epilepsy, ranging from 5.5 to 40.8%. Neurocysticercosis is considered as one of the leading causes of seizures in certain areas of Africa (Gelfand and Jeffrey, 1973; Grunitzky et al, 1991; Grunitzky et al, 1995; Avode et al, 1998; Druet-Cabanac et al, 1999). Onchocercosis and other parasites are also evoked as a potential cause of seizures in some areas, even though some authors do not find a tight correlation (Kabore et al; Newell et al, 1997; Kaiser et al, 1998; Farnarier et al, 2000; Druet-Cabanac, 2002).

Head injury, congenital CNS abnormality, tumours, vascular and metabolic disorders are increasingly being reported as causes of epilepsy in adults in the African Region (Ruberti, 1986; Matuja, 1989). Because of cultural factors, many consanguineous marriages are realised in many African ethnic groups, thus favouring genetic epilepsy which is not well documented yet (Chuke and Muras, 1977; Rwiza et al, 1992; Iloeje, 1991).

### 3.2.5 Outcome and prognosis

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The impact of epilepsy on long-term outcome, prognosis and mortality is not well documented in Africa. Studies about death among people with epilepsy are very rare in the AFRO Region. The outcome of the same clinical – epileptic or not – incident can differ from one epileptic patient to another, depending on the general conditions. This situation is reflected in the general mortality rate in Africa. However, patients with epilepsy showed an even higher mortality rate, double that of the general rural population of similar age such as found in rural Tanzanian areas and in Kenya (Jilek-Aall, Rwiza, 1992; Snow, 1994). Epilepsy-related deaths were proportionately higher after drug supply was stopped and among patients who were receiving drugs irregularly or who had only partial seizure control. The causes of death were epilepsy-related in 50% of the patients and were due to status epilepticus, drowning, burns, or sudden death. Similar data are reported from other African countries (Snow et al, 1994; Mbodj et al, 2000). In Ethiopia, during a period of 2 years follow-up, a death rate has been detected of 31.6 /1000 for people with epilepsy versus 16.4/1000 for general population (Tekle-Haimanot, 1990).

A unique follow-up, highlighting a long-term process, comes from Tanzania (Jilek-Aall, 1992). In a clinic founded in a rural community, approximately 164 patients were treated with phenobarbital for around 10 years (the “treatment period” was approximately 1960–1970). The area was revisited 20 years later to trace these patients. During “the treatment period” of the 164 patients, 52.4% achieved complete seizure suppression, 36.0% experienced reduction in seizure frequency, 7.9% experienced no change, and in 1 (0.6%) seizures were worse and 3% could not be accounted for. Twenty years later 110 had died, one third due to epilepsy-related causes, one third due to unrelated causes and for one third the cause of death was unknown. Of the 54 persons not known to have died, in 21 cases information was unavailable. Of 33 surviving and accountable persons 72% were seizure free.

In rural Mali, 80% out of 96 patients treated with



Phenobarbital became seizure free within one year (Nimaga et al, 2002; Farnarier et al, 2000). These authors have demonstrated that epileptic patients needed on average 416 tablets of 100 mg Phenobarbital per year.

The outcome of epilepsy could be the same in

every country in the world. It mainly depends on the accessibility, availability and follow-up of the control of the seizures with anti-epileptic drugs and the cure of the underlying aetiology if possible (Diop, 2000). This is the challenge in the African Region and it should be highlighted in a public health perspective (de Jong, 1996; Preux et al, 2000).

#### **Box 4: General causes of epilepsy**

*The causes of epilepsy are summarized in three general etiological groups. The first one is the threshold, which determines the susceptibility of individual brains to generate seizures in response to epileptogenic perturbations. This will determine what is called PRIMARY or IDIOPATHIC epilepsy, when it is not the result of some other brain abnormality. They are usually benign and often remit spontaneously or after uninterrupted pharmacological treatment with antiepileptic drugs (AED). The duration between onset and remission can vary from 2 to 12 years.*

*The second group is related to a specific epileptogenic abnormality, which could be an acquired lesion of the brain, congenital malformations of the brain or genetic disorders other than epilepsy. These SECONDARY or SYMPTOMATIC epilepsies are very common in developing countries, where they are responsible for the difference in terms of prevalence and prognosis. Risk factors are dominated by poor perinatal care, head trauma, and intracranial infection, including parasitic infestations (such as neurocysticercosis, neuromalaria), and these are far more common than in industrialised countries.*

*Their control requires, in addition to AED, specific care of the aetiology (medical and/or neurosurgical).*

*The third group is represented by epileptic disorders that are probably symptomatic, but the causes have not been identified with existing diagnostic means, and therefore they are called CRYPTOGENIC (which means hidden cause) with a high suspicion of a genetic (but non identifiable) factor.*

Adapted from: ILAE, 1989 and Engel and Pedley, 1997.

#### **Box 5: Reported causes of seizures and epilepsy regarding the age of onset in sub-Saharan Africa** (adapted from Genton, 1992 and reports from African teams).

*0 – 4 months: Neonatal asphyxia; perinatal traumatism; infections<sup>a</sup>; cerebral malformation; subdural heamatoma; hypoglycaemia; hypocalcemia; inborn errors of metabolism.*

*4 months – 2 years: Sequel of previous causes; infections<sup>a</sup>; vascular causes; inborn errors of metabolism; West syndrome.*

*2 – 10 years: Sequel of previous causes; idiopathic generalized epilepsy; infections<sup>a</sup>; post-traumatic epilepsy; intoxication; Lennox-Gastaut syndrome; inborn errors of metabolism; primary tumours.*

*10 – 20 years: Sequel of previous causes; idiopathic generalized epilepsy; post-traumatic epilepsy; intoxication including alcohol and other drugs<sup>b</sup>; infections<sup>a</sup>; malformations; Lennox-Gastaut syndrome; inborn errors of metabolism, malformations, neurodegenerative disorders.*

*20 – 40 years: Sequel of previous causes; post-traumatic epilepsy; brain tumours; alcohol; infections<sup>a</sup>; vascular diseases, tumours and abscesses, neurodegenerative disorders.*

*40 – 60 years: Tumours; alcohol; head trauma; infections<sup>a</sup>; vascular causes; metabolic disorders<sup>c</sup>.*

*> 60 years: Vascular causes and metabolic disorders<sup>c</sup>; primary and secondary tumours; neurodegenerative disorders; infections.<sup>a</sup>*

<sup>a</sup> Infections: mainly encephalo-meningitis (including HIV, bacterial, viral), septicaemia, malaria, other parasitosis (neurocysticercosis, amoebiasis, toxoplasmosis, trypanosomiasis, nematodosis, trematodosis), possibly onchocerciasis

<sup>b</sup> Addictive; traditional and modern medicines

<sup>c</sup> Metabolic disorders: mainly diabetes

## ■ 3.3 Epilepsy management in the African Region

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### ■ 3.3.1 *The treatment gap*

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During a workshop in Marrakech (Morocco) in May 1999 with African and international experts organized by the International League Against Epilepsy, a consensual definition of "Treatment Gap" has been adopted: *"The difference between the number of people with active epilepsy and the number whose seizures are being appropriately treated in a given population at a given point in time, expressed as a percentage."* (Meinardi et al, 2001). It is estimated that 80% of the global health burden represented by epilepsy is borne by the developing world, where 80% of people with epilepsy reside and do not receive modern treatment, or are not even identified. Poor infrastructure, insufficient availability of drugs and scarcity of trained medical personnel are all relevant factors for this situation. Some potential causes include the level of health care development, cultural beliefs, economy, distance from health care facilities, the supply of AED's, and a lack of prioritization in national health policies.

### ■ 3.3.1.1 *The cultural context*

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Epilepsy is perceived as an "African" ailment, a manifestation of supernatural forces, traditionally looked upon as caused by ancestral spirits or attributed to possession by evil spirits (Arborio et al, 1999; Reis, 1994; Nubukpo, 2002). In many parts of Africa, syncretic amalgamation of indigenous traditions with Judeo-Christian or Islamic doctrines have influenced popular attitudes toward epilepsy (Jilek-Aall, 1999; Milieto, 1981). The levels of literacy and knowledge, and the possibilities for a family to acquire other background knowledge, may also influence cultural beliefs and choices. All these reasons lead to the family and the patient to first consult the traditional healers and follow their recommendations for a long period of time (Dale, 1984).

### ■ 3.3.1.2 *Structural factors*

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In several countries, the government no longer provides free health care. The population has to pay more for health care. Health insurance is poorly developed. It should also be stated that the World Bank's structural adjustment programmes hinder



*The doctor's visit*

many developing countries' health sectors. In sub-Saharan Africa incomes, export, investment, health expenditure, and education expenditure have decreased, whereas debt, ecological damage, malnutrition, and morbidity have increased. Many health activities have become unaffordable for the patient because of health system reforms in the majority of the countries. One of the reasons for not seeking medical treatment invoked among others by the population is financial.

### ■ 3.3.2 *The time between onset of seizures and medical treatment*

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The anthropomedical context in which diseases occur in Africa often leads to a double utilization of "western" and traditional medicines by most people suffering from epilepsy. This is particularly the case when the illness becomes chronic. The mean duration before first attendance of modern medical settings depends on the area of residence (urban or rural), the impact of cultural beliefs and the financial means. For example, reports from Malawi and Senegal reveal that this period can respectively reach an average of 6.5 and 13.4 years (Watts, 1992; Diop, 1998). Sociocultural factors, and in particular the supposed causes of epilepsy, can explain why patients first seek advice from traditional therapists and healers (Danesi and Adenbunji, 1994; Dale and Ben-Tovim, unpublished data). Traditional methods are numerous and reflect directly how epilepsy is perceived in different cultures. In general it is only after several months or years of trial and error that the patient eventually is taken to hospital or a rural health facility (Danesi and Adenbunji, 1994; Uchoa et al, 1993). However, the role of traditional healing should not be completely discredited as in many instances it plays a crucial role. Improving the cooperation with the traditional healers in respect of everyone's competence and recognition, could lead to better referral of cases which are resisting their therapeutic methods.

### ■ 3.3.3 *Pharmacotherapy*

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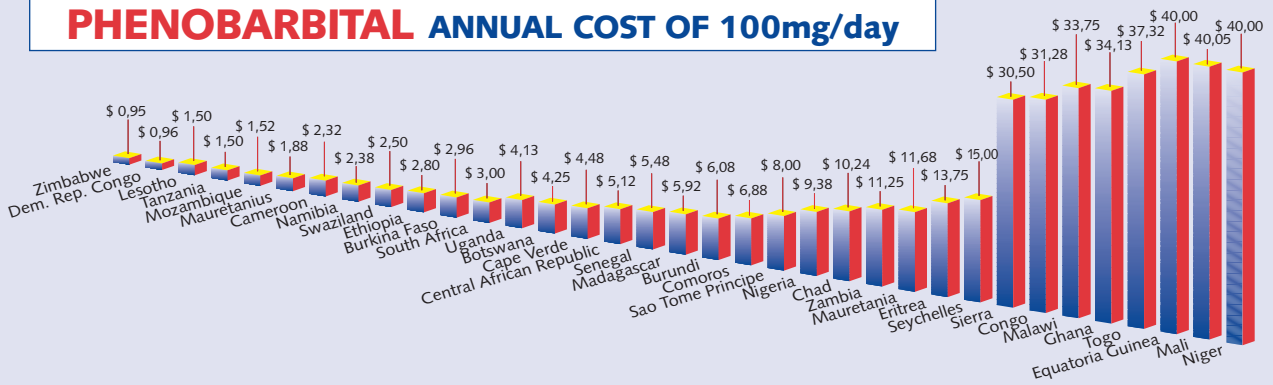
The most prescribed anti-epileptic drugs in Africa are: phenobarbital and phenytoin (the latter is available only in some countries). These two drugs are the cheapest and are prescribed in 65% to 85% of treated epileptic patients (Diop, 1998). They are available in most health care establishments via the Bamako Initiative drug supply system and/or in community pharmacies.

Many cases of swollen and irritated gums are observed in patients treated with phenytoin who do not have a good mouth and teeth hygiene (Ogunbodede et al, 1998). The annual cost of seizure control with Phenobarbital, at 100 mg per day, ranges from US\$ 1.00 to 150.00. For Phenytoin, this is US\$ 2.00 to 69.00. Carbamazepine (CBZ) is the third drug, and is prescribed in only 5 to 20% of reported treated cases; Its annual cost ranges from US\$ 2.00 to 460.00. Valproate (VPA) is prescribed in 5 to 15%, but is less widely available, and the annual costs for 1500 mg/day are also much higher than those of the aforementioned drugs, ranging from US\$ 31.00 to 942.00 (Table 5)\*. For status epilepticus, injectable diazepam (DZP) is used when available (Mbodj et al, 2000). The provision of AED's through government-funded schemes is in some cases impossible. Although governments may lack resources, it may be equally true that individuals are either unable to pay for AED's from their own incomes, or such costs cause financial hardship. One may remember that 61 to 72.8% of the population in the poorest countries of the African region live on less than US\$ 1.00 per day (UNDP, 2001). This is a convincing fact, underlining the need to use Phenobarbital as the first choice in public health intervention for epilepsy.

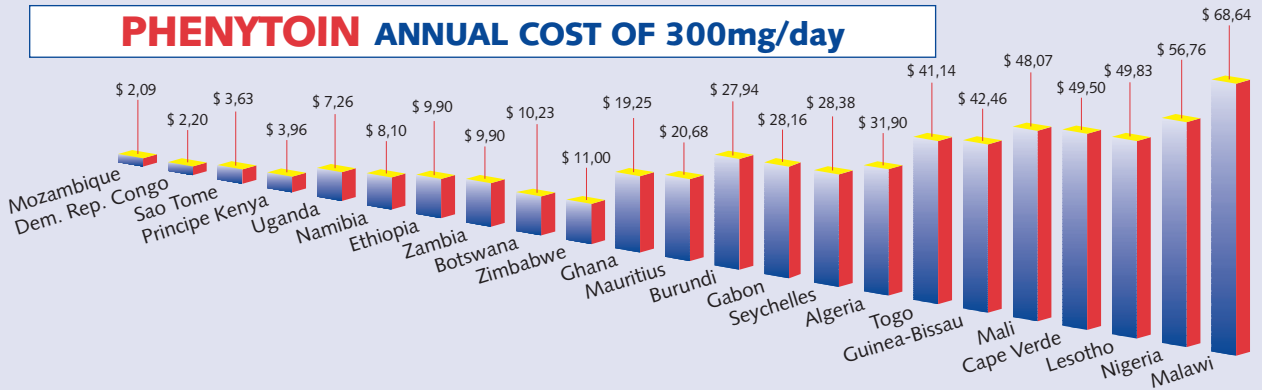
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\* Table 5, page 37

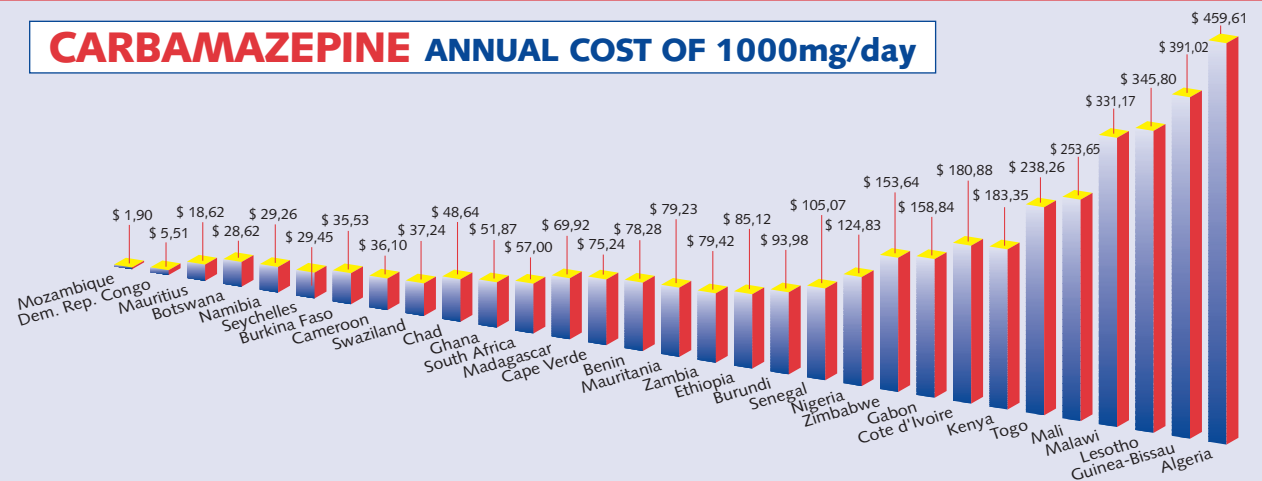
## PHENOBARBITAL ANNUAL COST OF 100mg/day



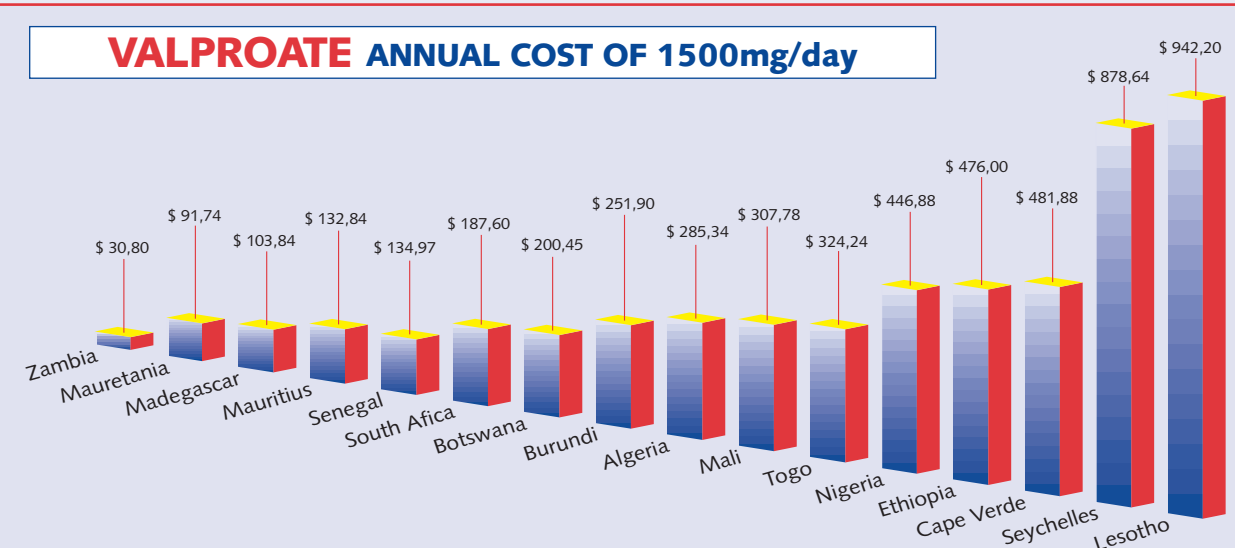
## PHENYTOIN ANNUAL COST OF 300mg/day



## CARBAMAZEPINE ANNUAL COST OF 1000mg/day



## VALPROATE ANNUAL COST OF 1500mg/day



Adapted from table 5

#### ■ 3.3.4 Other treatments for severe epilepsy

When people with epilepsy continue to have frequent seizures despite multiple drug therapy, epilepsy surgery may be indicated. In many parts of the world, epilepsy centres are performing surgery routinely with good results in those selected from the 25% of people with epilepsy who do not benefit from drug therapy and who are candidates for such operations. In the AFRO region, two centres exist in South Africa. Neurosurgeons in other countries do remove lesions, such as neoplasms and post-traumatic scars, which cause seizures (Girard et al, 1973; Ruberti, 1986; Kalangu, 2000). The sophisticated diagnostic equipment required is already available in some other African Countries such as, Kenya, Nigeria and Zimbabwe. Surgery could represent a significant improvement in the quality of life for some of the 20 to 30% of people with epilepsy who continue to have seizures while taking appropriate medication. Centres in other low-income countries, for instance Columbia, are providing an example to Africa.

An alternative to surgery is vagus nerve stimulation. This involves implantation of an expensive device. This limits its applicability to Africa. Another alternative, especially in children with drug-resistant epilepsy, is the use of a ketogenic (very high fat content) diet. Although it is expensive and difficult to tolerate, reduction in seizures frequency have

been consistently reported. There are no reports on the use of this method in Africa.

#### ■ 3.3.5 Rehabilitation

Few African countries have established rehabilitation or resocialization programmes for persons living with epilepsy. In most instances traditional healing is the first treatment sought. In some countries, the traditional belief systems endorse discrimination against people with the condition, leading to their exclusion from mainstream society and restrictions on their access to basic human and civil rights. However, the role of traditional healing should not be completely discredited as in many instances the person with epilepsy obtains a degree of secondary benefit from this form of intervention in the way of reassurance and emotional support. Efforts should be made to integrate traditional and western interventions in a way that provides a range of services offering holistic support and care for the person with epilepsy and his or her family (Feksi et al, 1991). These would include advice, counselling, social support, school to work transitioning, job creation and training, rehabilitation and community integration. The challenge is how to reconcile the conflicting convictions that guide the traditional and scientific treatment concepts.



*Treating epilepsy*

### ■ 3.3.6 *Stigma, discrimination and human rights violations experienced by people with epilepsy in the African Region*

Epilepsy is well known in African societies. As in many other societies, people with epilepsy, particularly those who have generalized tonic-clonic seizures, experience discrimination in several areas of life, even from some health professionals. Epilepsy is often perceived as a mental illness or contagious disease. Involuntary behaviour associated with some seizures, such as incontinence, tends to invoke fear and misunderstanding. In some African societies, the breath, blood, sperm and genital secretion of people with epilepsy are also considered to be highly contagious (Nubukpo, 2000). This leads to unacceptable responses such as rushing from a person experiencing a seizure without offering any help, due to irrational fears of contamination from bodily fluids. Death, drowning, burning and other injuries may result from such situations.

Discrimination and exclusion are daily frustrations for people living with epilepsy. Discrimination on the grounds of epilepsy manifests itself in all spheres of life, including health care and educational systems, employment, and social and family life. For example in Côte d'Ivoire (the Ivory Coast), people with epilepsy have to wash their clothes separately and ladies are not allowed to cook meals for the group. Workers must use their own tools and may not mix them with the group. In Burkina Faso's Nankara ethnic group, people with epilepsy are not allowed to make speeches during traditional assemblies. When they die, they are not buried, but are thrown into the mountains or the sacred bush. In many African ethnic groups, people with epilepsy cannot marry, although this is not specific to the African continent. They may also not be permitted to participate in traditional ceremonies celebrating the passage to adulthood. Children with epilepsy often face discrimination and isolation at school. This results in low self-esteem and under-achievement at school. Surveys conducted in schools revealed a high rate of social withdrawal among children with epilepsy (Agbohoui, 1994). In certain instances children are denied access to education out of shame on the

part of the family or the school's refusal to accommodate them for fear of "contaminating" other pupils. Some children experience cognitive difficulties due to the side effects of AED's or due to the severity of the condition itself (Agbohoui, 1994).

Ignorance about epilepsy and the effects of some AED's on the part of teachers often leads to misinterpretation of certain behaviours, such as drowsiness, memory impairment and attention deficits being mistaken for laziness and lack of interest.

Regulations regarding epilepsy and driving are not uniform across the region. However, in general, there is little appreciation of the curtailment of rights imposed by unduly harsh and unsubstantiated limitations on the issuing and retention of driver's licences for people with epilepsy.

#### **Box 6: Example of a "good practice" intervention in the Sotoba District**

*Sotoba is a district in the northern part of Togo where intersectoral collaboration can be shown as a good practice to bring epilepsy out of the shadows and people living with epilepsy out of marginalization. A project brought together members of the Togolese Association against Epilepsy, community based agents trained in epilepsy issues, and members of the national mental health programme at Ministry of Health level. This group decided to bring together people living with epilepsy and not receiving any type of care (mainly living in the streets) and provide them with essential care including medication. After 18 months of integrated care (medication and psychosocial care, support to the families) results were quite encouraging. Social reintegration was possible in 35 adult cases; we can say that these 35 cases were brought "out of the shadows". About 180 children and adolescent cases were followed and around 60% of these cases are seizure free. There is hope for an improved quality of life.*

## 4. Initiatives to address epilepsy in Africa

### ■ 4.1 WHO Regional Strategy for Mental Health

Taking into consideration the fact that 12.5% of the global burden of disease is due to mental and neurological disorders worldwide and the resolutions of the World Health Assembly, the WHO Regional Committee for Africa and the United Nations General Assembly invited Member States to consider Mental Health in general as an essential part of the aim of "health" defined by WHO as "a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity". A Regional Strategy for Mental Health for the period 2000–2010 has been conceived and adopted by the Regional Committee at its 49th session (WHO Regional Office for Africa, 2000). The origin for the implementation of the AFRO Regional Strategy for Mental Health has been determined by resolution AFR/RC49/R3. This Strategy Document is meant as a tool for assisting African Member States and their partners to identify priorities and strengthen national policies dedicated to this issue, which includes epilepsy, at various levels of the health system, with particular emphasis on district and community levels. It covers:

- policy formulation and programme development;
- capacity-building;
- advocacy and social mobilization;
- information and education;
- research;
- partnerships and collaboration;
- technical cooperation among countries of the AFRO Region and with WHO collaborating centres and other programmes of the Regional Office.

It describes the main objectives in terms of prevention control and care that every African country must reach from 2000 to 2010, urging all Member States to:

- take measures to reduce the incidence and prevalence of specific mental and neurological disorders, including epilepsy;
- offer an equitable access to cost-effective mental, neurological and psychosocial care;
- improve the quality of life of people suffering from such disorders through community-based rehabilitation to change people's negative and stigmatising perception of mental and neurological disorders;
- formulate or review existing legislation and if necessary adapt it to the support of such diseases.

The Epilepsy section of the Regional Strategy has been presented by the Mental Health Unit of the Division of Non-Communicable Diseases, WHO Regional Office for Africa, as an example during the Afro exhibition on Health at the New York meeting on "Poverty and Health, Challenges for Africa Development" on November 2001. This meeting's goal was to raise awareness for health programme fundraisers.

### ■ 4.2 The Global Campaign Against Epilepsy

#### ■ 4.2.1 The mission statement

The Campaign's mission statement is "to improve the acceptability, treatment, services and prevention of epilepsy worldwide", in order to address discrimination against those with epilepsy, and to diminish the treatment gap in the developing regions of the world. The main strategy of the GCAE consists of two components, the provision of a platform for general awareness and assisting departments of health in developing National Epilepsy Programmes. In order to increase awareness of the problems caused by epilepsy and the means available to deal with them, conferences have been organized between key persons in health care administration and government and experts in the field of epilepsy. These conferences were held in all six WHO Regions (Africa, the Americas, the Eastern Mediterranean Region, Europe, South East Asia and the Western Pacific Region), and have resulted in Regional Declarations. The concept of Regional Declarations on Epilepsy pioneered by the European Declaration (in Germany, October 1998) has been elaborated with the goal of identifying problems and proposing solutions for ministries of health and other health care organizations. In 1999, WHO raised the Global Campaign against Epilepsy to cabinet level, making it one of its highest priority projects. Every regional office of WHO has pledged to commit personnel and resources to this Campaign.

The launch of the second phase of the Campaign was organized at WHO Headquarters with the participation of the Director General of WHO, Dr. Gro Harlem Brundtland, in February 2001. During

this historical event, Dr. Brundtland said: “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”.

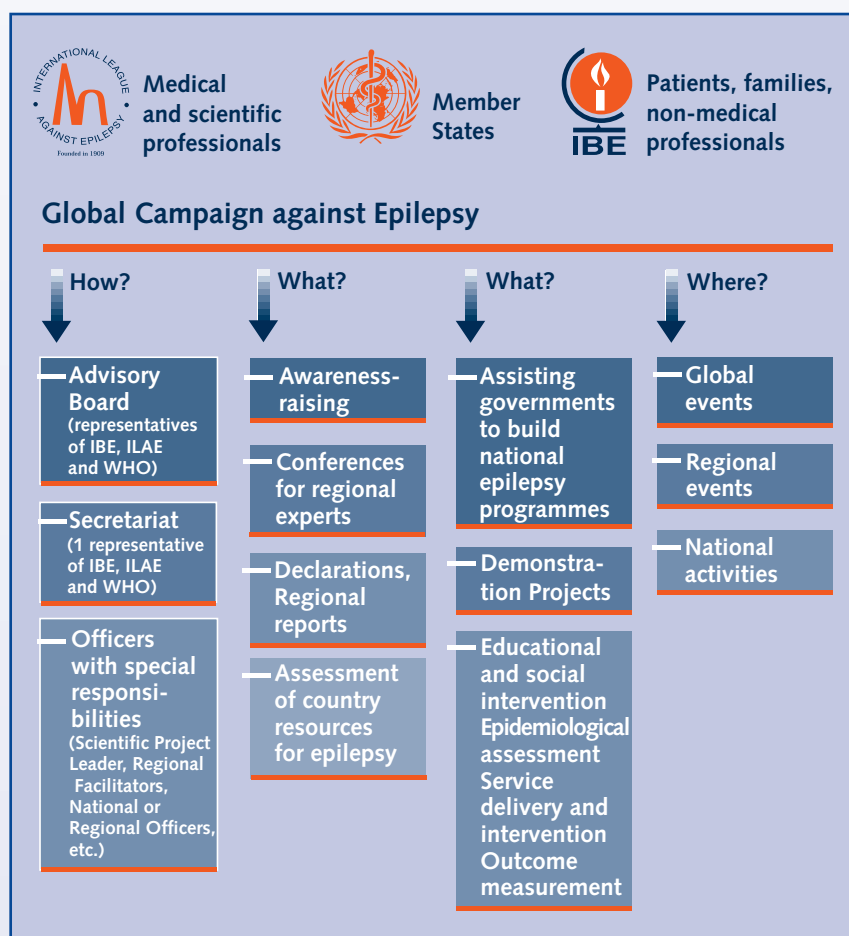
Among the major instruments that have been set up by the GCAE to underline and achieve its aims are the so-called Demonstration Projects. They have been designed to identify people with epilepsy and offer them appropriate treatment. The specific objectives are: to develop models for the promotion of epilepsy control worldwide; to reduce the treatment gap and social and physical burden; to educate health personnel; to dispel stigma; to eradicate preventable causes of epilepsy and to integrate epilepsy care in national health systems.

Three organizations collaborate in the Global Campaign Against Epilepsy: WHO (specialized agency of the United Nations, with 192 Member States), ILAE (with member organizations in circa 100 countries) and IBE (with member organizations in circa 100 countries). ILAE member organizations consist of professionals concerned with medical and scientific aspects of epilepsy, while those of IBE are concerned with social aspects and the quality of life of people with epilepsy.

In June 1997, these three partners launched the Global Campaign Against Epilepsy simultaneously from Geneva, Switzerland, and Dublin, Ireland, during the 22nd World Congress on Epilepsy. A Secretariat was established consisting of a representative from each of the three organizations, which oversees the day-to-day running of the Campaign. The Secretariat is accountable to an Advisory Board composed of two representatives of each of the three bodies. Both the Secretariat and

the Advisory Board members are accountable to their respective organizations. WHO works through its regional offices and country representatives. IBE and ILAE work through their regional commissions, their resource-oriented and problem-oriented commissions, and their national member organizations.

The Campaign structure and activities are outlined in the figure below.



Global Campaign Against Epilepsy Brochure

#### 4.2.2 The implementation of the GCAE in the African Region

Since WHO Cabinet approval in December 1999, collaboration with and support for the Campaign has been strengthened through the involvement of the Regional Offices of WHO.

WHO has placed Mental Health very high on its agenda as evidenced by the fact that it was made one of the eleven global priority areas for 2002–2003 for the Programme Budget adopted by



the 106th session of the Executive Board, as well as one of the priorities for the same period, endorsed by the 50th session of the (African) Regional Committee in September 2000. Epilepsy is part of this. Since the launch of the second phase of the Campaign 20 out of the 46 countries have embarked on some activities related to the Global Campaign Against Epilepsy.<sup>\*</sup>

Most of these activities have been undertaken by very active NGOs and associations with almost no support from the national health authorities. This is why the WHO Regional Office for Africa decided to use its leadership role in health issues to sensitise the decision-makers and make them understand that:

- epilepsy is a public health concern in the African Region;
- most causes of epilepsy in Africa are preventable;
- epilepsy can be treated;
- people living with epilepsy can enjoy better lives and contribute to social and economic development.

The WHO Regional Office for Africa is highly committed to translate the recommendations from experts in the field of epilepsy into concrete actions and to build up strong and sustainable partnerships towards more and more successes in the prevention and management of epilepsy.

In May 2000, an international meeting “Epilepsy as a Healthcare Priority in Africa” was held in Dakar, Senegal, with the aim to increase public and professional awareness of epilepsy as a treatable brain disorder and to raise epilepsy to a new plane of acceptability in the public domain. Around 120 delegates came from some 25 countries and from international organizations such as IBE and ILAE and the neuroscience branch of WHO in the region as well as from WHO Headquarters in Geneva, Switzerland. It was the first time ever in Africa that contacts took place between representatives of the Executive Committees of IBE and ILAE and professionals from different sectors in the management of epilepsy. As a result of this conference an African Declaration on Epilepsy was developed and adopted (see Annex 1).

\* Benin, Burkina Faso, Cameroon, Chad, Congo, Ethiopia, Ghana, Kenya, Lesotho, Mauritius, Mozambique, Rwanda, Senegal, South Africa, Swaziland, Tanzania, Togo, Uganda, Zimbabwe

This Declaration has been widely disseminated in English and in French to all Member States in Africa and to international institutions and organizations involved in epilepsy care.

A number of technical consultative meetings were convened by the WHO Regional Office for Africa in close collaboration with the Campaign Secretariat. Representatives of almost 30 countries\*\* in the region participated in these meetings. Some of the main objectives of these meetings were:

- to facilitate the implementation of the Global Campaign against Epilepsy in the countries of the African Region;
- to reach consensus on the need to consider epilepsy as one of the priorities of the Mental Health area of work in the participating countries;
- to identify priority interventions for the development of country action plans in line with the African Declaration on Epilepsy.

During the meetings the enormous challenges were pointed out, including the problems and possible solutions concerning cultural beliefs, availability, affordability and accessibility of anti-epileptic drugs and the role of the main partners of the GCAE (IBE, ILAE and WHO) (see Chapter 5).

The following recommendations were agreed upon:

- development of strategic partnerships;
- epilepsy education for various target groups;
- research and training;
- prevention, both of causes and consequences;
- development of guidelines for epilepsy management;
- collaboration with the traditional healers;
- setting up of Drug Banks following the Chilean Model, the Uganda experience and exploring linkages with the Bamako Initiative;
- under the GCAE umbrella, investigating possibilities to acquire affordable AED drugs *to reduce the treatment gap*;
- empowerment of people living with epilepsy and their families through the encouragement of income generating projects;

\*\* Cameroon, Ethiopia, Lesotho, Kenya, Mozambique, Senegal, South Africa, Swaziland, Tanzania, Togo, Uganda and Zimbabwe, Algeria, Benin, Burkina Faso, Burundi, Cape Verde, Chad, Congo-Brazzaville, DP Congo, Côte d'Ivoire, Gabon, Guinée Conakry, Mali, Mauritania, Niger, Rwanda, Senegal, and Togo,

- increased participation of African delegates at the international conferences on epilepsy – the “*Star for Africa*” initiative.

Finally the protocols as well as the timeframes of the Demonstration Projects in the African Region were discussed.

For the experimental phase of the Global Campaign against Epilepsy in Africa, these Demonstration Projects have been set up in two countries: Zimbabwe and Senegal (the selected areas are Hwedza in Zimbabwe, a communal farming area, and Pikine in Senegal, a suburban area of the capital city Dakar), with the aim to show that concrete and simple actions can lead to clear-cut positive effects.

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

Demonstration Projects start in a representative region of limited size. This is the research phase. The aim is to investigate the impact of local conditions on general strategies to improve epilepsy care. Results of the research phase are used by National Health Authorities to plan and implement services and awareness raising about epilepsy all over the country. Also the results of the implementation phase are assessed in order to develop a National Programme on Epilepsy. Specific aims of Demonstration Projects are:

- to estimate the prevalence of untreated active epilepsy;
- to identify the economic and psychosocial burdens of the condition;
- to apply training programmes for health professionals and assess the efficacy and validity of these programmes;
- to promote a change of attitude in the community and evaluate the tactics that have been used to achieve a change;
- to eradicate preventable causes of epilepsy.

Criteria for country selection are:

- the likelihood that results of the Demonstration Project can be utilized by other countries;

- the availability of political and personal contacts;
- the willingness to participate;
- the availability of a WHO centre or country representative;
- an IBE and an ILAE member organization, or groups that have the potential to form a member organization;
- regular and basic antiepileptic drugs (AED) supply;
- the facility of communication.

#### ■ 4.2.3 Strategy

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In general terms each Project has four aspects:

- 1) Assessing whether knowledge and attitudes of the population are adequate, correcting misinformation and increasing awareness of epilepsy and how it can be treated (Educational and Social Intervention).
- 2) Assessing the number of people with epilepsy and how many are appropriately treated (Epidemiological Assessment and Case ascertainment).
- 3) Ensuring that people with epilepsy are properly served by health personnel equipped for their task (Service Delivery and Intervention).
- 4) Analysing outcome and preparing recommendations for those who wish to apply the findings for improvement of epilepsy care in other countries (Outcome Measurement).

A number of evaluations are carried out to measure the overall effectiveness of the project\*:

- the number of treated patients before and after interventions;
- the number of trained persons;
- the number of documents and programmes produced through TV, radio, newspapers and other communication means;
- the quantity of AED commanded by health establishments and their disbursement;
- changes in knowledge, attitude and practice (KAP) among medical and paramedical personnel, social workers, school teachers, and selected representatives of the general population.

The projects are intended to last approximately 18 months and if successful they may be pursued further.

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\* Further details are available from the Campaign Secretariat

## 5. Challenges

The major challenges for epilepsy in the African region are:

- Bridging the treatment gap
- Preventing symptomatic epilepsies which are mainly public health problems
- Rights promotion for people with epilepsy by
  - a) empowerment of individuals and communities with appropriate knowledge and skills;
  - b) advocacy and self representation;
  - c) provision of appropriate support and care;
- Research
- Partnerships.

### ■ 5.1 Treatment gap

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In order to meet and solve the huge challenge of reducing the treatment gap in the African Region, action will need to be taken. This is a task for professionals from various sectors, who manage every aspect of the lives of people with epilepsy using a multidisciplinary approach (health, education, social and professional activities and psychology). Trained health and social workers must cooperate with informed patients and families, communicators, community and opinion leaders, with the support of Governments, national and international institutions and NGOs, the GCAE, bilateral and multilateral partners and pharmaceutical companies.

#### ■ 5.1.1 Political commitment

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One of the first challenges is to increase the awareness of the decision-makers. One conclusion of the Marrakech meeting on the "Treatment Gap" in May 1999 was: *"A commitment to resources for epilepsy treatment must be gained from governments and international health organizations. Political patronage must ensure that epilepsy remains on the agenda and that essential drug supplies are assured."* Every single person with epilepsy who becomes seizure-free is a potential economical and social contributor. Indeed the World Bank has prioritized epilepsy as a highly cost-effective condition to treat. What is also true is that any action against the main causes of epilepsy will not be sustainable if it is not included as a component of the National Health Plan whose goal is registered

in a Public Health Policy determined by the Ministries of Health of each country. The nationwide level of development too is important as it influences the knowledge about the problem and its potential solutions. Important aspects to consider are: literacy, cultural beliefs, distance from modern healthcare facilities, competing threats to the health of the population.

#### ■ 5.1.2 Access to epilepsy care

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This concerns the problem of the availability of know-how at the community health care level. It has been shown that a reasonable level of seizure control can be achieved by primary healthcare workers. However, given the inappropriateness of vertical programmes (i.e. primary healthcare workers only involved in epilepsy care), sufficient back-up for all primary health care workers should be available in order to give epilepsy care its proper place among their many other duties.

#### ■ 5.1.3 Education

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Various groups (decision makers, professionals, people with epilepsy and their families, teachers, and primary health care workers, police and the general public) have to be targeted. The community should be given adequate information to reduce stigma related to the condition. Epilepsy is not contagious, epilepsy is treatable, and people with epilepsy can enjoy better lives and become valuable members of the community. Training of health care workers is essential if people with epilepsy are to be correctly diagnosed and appropriately treated. Improving local competence at primary and secondary health care levels is a necessity. Education programmes and information for professionals could benefit from the new tele-medicine system via Internet. This can reduce long trips for patients seeking consultation and decrease the cost of epilepsy health care.

The following measures can be taken:

- setting up a training programme on epilepsy for general MDs and medical specialists, nurses and midwives, social workers and school teachers;

- developing or adapting existing guidelines for epilepsy management;
- strengthening the capacity of medical schools in the Region to train specialists in the fields of neurology, neurosurgery and psychiatry and increase the time devoted to epilepsy in current curricula.

#### ■ 5.1.4 Cultural environment

The aim of reducing the treatment gap needs to take into consideration the cultural environment. Information and education of the public in general is important in order to enable and empower people to make informed choices. Cultural aspects should be studied with regard to patients' perceptions, attitudes and practices in relation to epilepsy, as well as their socio-familial relations. They provide the background for appropriate information, education and treatment programmes to be adapted in a holistic way to cultural specificities with a great chance of success. Furthermore research should be done to find out how apparent conflicts between cultural and scientific concepts can be resolved.

#### ■ 5.1.5 Collaboration with traditional healers and community leaders

Because the majority of patients will consult traditional healers, a noncompetitive relationship should be encouraged. Sharing information and research and offering training to the traditional healers would strengthen this collaboration. Many field experiences also emphasize that working closely with traditional healers, community and religious leaders would give the primary health care worker a better opportunity to gain acceptance from the community and modify certain harmful practices.

#### ■ 5.1.6 Community-based approaches

This is increasingly used as a model of service delivery for health and disability services in developing countries. These approaches are based on the fact that most people with disabilities in low-income countries live in rural areas and are

exposed to poverty. In addition to disability, they usually have to face other problems in their lives. Attention to cost-effectiveness by the community is enhanced, as local resources raised by the family and social group are at stake.

Interventions aim at: counselling families, offering first aid advice, supporting the family, making a neuro-developmental assessment of the children, designing an individual programme to promote their rehabilitation, assessing what their social relations are like, acting as advocates within the community to get them back into school, getting them to play with other children opening up opportunities for them, acting as a medical liaison and follow up treatment. It means that people with the most needs will be assessed appropriately and receive the care they deserve. By integrating members of the community as assistants in the distribution of the medication, community participation could be gradually enhanced and improve compliance.

## ■ 5.2 Prevention and control

Most of the causes of epilepsy in Africa are preventable. Collaboration with the different programmes such as safer pregnancy, Integrated Management of Child Illnesses (IMCI), child and adolescent health, prevention and control of some communicable diseases, immunisation, prevention of head trauma, alcohol and drug abuse should therefore be a priority. Early detection and appropriate treatment will reduce disabilities caused by epilepsy. In turn, epilepsy is an important outcome measure for these programmes.

#### ■ 5.2.1 Integration of epilepsy prevention in public health interventions

As many cases of epilepsy in developing countries arise from other health problems, the epilepsy programme should be included in primary health care national plans and coordinated with other public health programmes that take place at a government and community level. In particular, the plans directed towards mother and child, pregnant women and first decade paediatric health, should

take into consideration that complications in the peri-partum period are the leading causes for future epilepsy in African and developing countries. Major measures for primary prevention could consist in improving awareness and taking action on:

- increasing and improving prenatal consultation and medically assisted delivery;
- improving maternal and infant immunisation;
- prevention and better management of work and road accidents by making the wearing of helmets obligatory;
- avoiding alcoholic and environmental toxicology;
- highlighting, managing and preventing infectious diseases that affect the brain;
- preventing consanguine marriages.

### ■ 5.2.2 Management

Apart from convincing people with epilepsy to take modern medicine, it is essential to:

- strengthen the availability of Phenobarbital at all levels of health care, in line with the Bamako Initiative list for people with epilepsy;
- develop the utilization of generic drugs with a periodic control of their quality;
- tolerate non dangerous traditional medicine, but insist on the necessity not to stop modern medical drugs;
- set up drug banks via an agreement between ILAE/IBE national chapters and drugs suppliers to obtain anti-epileptic drugs at the lowest cost and make these available and accessible for all patients with epilepsy. The system should raise its own funding mechanism and become sustainable and as autonomous as possible.
- equip major tertiary-level specialized national health establishments with an EEG service, a CT scanner and a drug monitoring laboratory.

### ■ 5.3 Rights promotion

In many instances people with epilepsy are denied or restricted access to fundamental human and civil rights. This is unacceptable. The rights of people with epilepsy need to be promoted and they need to be enabled to exercise these rights.

### ■ 5.3.1 Empowerment of individuals and communities with appropriate knowledge and skills

People with epilepsy are entitled to the rights to education, training and employment. In instances where these rights have been denied, or their epilepsy condition has inappropriately or excessively restricted their accessing of these rights, corrective actions need to be taken.

Empowerment and capacity building programmes should focus on:

- Epilepsy knowledge and information supported by an adapted communication network
- Life skills
- Vocational skills
- Self management skills

For promoting education and public awareness about epilepsy, programmes should be directed at people with epilepsy and their families, and target groups such as employers, health care workers, teachers and the general public. Within these programmes, the following activities might be included:

- Information about epilepsy and treatment options for people with epilepsy themselves
- A National Epilepsy Day observed by all African countries with the endorsement of WHO/Ministries of Health
- Utilization of local cultural and social networks, media (TV, radio, newspapers)
- Production of materials such as tapes, videos, brochures, posters, t-shirts
- Endorsement by famous key persons
- Specific epilepsy education programmes for various target groups: people with epilepsy and their families, teachers, primary health care workers, police and the general public.

### ■ 5.3.2 Advocacy and self-representation

People with epilepsy have the right to appropriate advocacy actions to protect their rights, either through consumer groups advocating on their behalf or, preferably, through self-representation of their interests, needs and aspirations. In instances where rights have been violated, consumer groups

acting for people with epilepsy should be encouraged to address the situation, initially through a process of constructive negotiation but not excluding litigation, where indicated. In each country there should be a lay organization concerned with epilepsy.

### ■ 5.3.3 Provision of appropriate support and care

People with epilepsy have the right to appropriate support and care programmes to enable them to participate fully in society and to fulfil their potential. Interventions should include: counselling, advice, and support to the person with epilepsy and the family. It should also enable people to attain and retain appropriate placements in education, training and employment facilities. The needs of people with epilepsy should be assessed in order that they receive the appropriate care and support services.

Community Based Care (CBC) is the preferred model of service delivery for health and disability services in developing countries. This approach is based on the fact that most people with disabilities in low-income countries live in rural areas and are exposed to poverty. In addition to disability, they usually have to face other difficulties in their lives. CBC is cost-effective because the approach uses local resources raised from family and social groups. Rather than excluding people with epilepsy by placing them in institutional facilities, CBC enables people with epilepsy to remain within their communities and to participate in mainstream activities. Mechanisms should be in place to provide CBC with the knowledge and means necessary to serve people with epilepsy.

### ■ 5.3.4 Provision of a supportive environment

In order to promote the rights of people with epilepsy, an appropriately supportive environment should be created. This would include:

- Addressing legal and social discrimination against people with epilepsy at all levels, including within the community, in schools and employment.
- Empowerment of people living with epilepsy and their families through the provision of psychosocial rehabilitation and income-generating projects.

- The involvement of all role players who are able to contribute to interventions which promote the full integration of people with epilepsy into society.
- Ensuring that awareness of and sensitisation to the needs of people with epilepsy is integrated in all public sectors, such as education, employment, health and the legal system.

## ■ 5.4 Research

There is a huge need to improve research on: the epidemiology, outcome/mortality, sociology, psychosocial rehabilitation and the genetics of epilepsy in the African region, the lack of treatment compliance, the potential of African traditional pharmacopoeia against epilepsy and the burden of epilepsy.

- Research tools should be standardised and validated.
- Research should be performed according to international guidelines of ethical conduct and good practice.

## ■ 5.5 Partnerships

Partnership is a key element for the success of interventions. Therefore the following actions should be implemented:

- Improve communication and networking with international epilepsy institutions
- Integrate with existing programmes, such as the African Decade on Disability
- Support IBE/ILAE chapters twinning arrangements across developed/developing country boundaries
- Encourage the public sector, the private sector and partners to develop and participate in local activities of the Global Campaign Against Epilepsy in the African Region
- Encourage regional and continental collaboration to achieve the goals of the African Declaration on Epilepsy.

## 6. Actions to be taken

During the technical consultative meetings with experts in epilepsy which were organized jointly by WHO, IBE and ILAE, concrete actions by all field actors to further assist countries in the African Region to implement the GCAE were identified:

### 6.1 Ministries of health

- To advocate at country level for epilepsy to be one of the priority domains in the existing mental health programmes.
- To integrate epilepsy-related interventions in the existing primary health care system.
- To collaborate with other ministries with respect to social aspects of epilepsy.
- To commit resources to epilepsy activities.

### 6.2 National focal persons

- To set up in each Member State a national organization for epilepsy (local chapter of ILAE or IBE) to act in partnership with Ministries of Health and WHO.

### 6.3 National organizations for epilepsy

- To provide (guidance about) support and care.
- To advocate in respect of civil, education, employment and health rights.
- To raise awareness and educate about epilepsy.
- To inform and educate people affected by epilepsy in order to enable them to make informed choices.
- To increase social mobilization and empowerment of persons affected by epilepsy.
- To advance and disseminate knowledge concerning epilepsy.
- To encourage and carry out research.
- To promote prevention, diagnosis, treatment and care.
- To provide continuous professional education and training.
- To network with similar organizations within the Region and worldwide.

### 6.4 Country offices

- To collaborate with national epilepsy organizations.
- To liaise between WHO and the country authorities in relation to activities on epilepsy.
- To commit resources to epilepsy activities.

### 6.5 WHO Regional Office for Africa

- To provide technical and financial support to countries for activities of the GCAE.
- To update and disseminate the information on epilepsy activities using any available means.
- To advocate the establishment of an African Epilepsy Day.
- To develop collaboration between Mental Health and other Divisions, Units and Programmes that could be involved in specific aspects of the process, i.e.: Communicable Diseases, Health Sector Reform, Traditional Medicine, Oral Health, and Health Promotion, Mother and Child Care, Disability Prevention and Rehabilitation.
- To monitor the implementation of the recommendations.

### 6.6 WHO Headquarters

- To continue to support resource mobilization for the implementation of activities at regional and country levels.
- To continue to provide support on data collection (the already available questionnaire on country resources for epilepsy to be available in the other working languages of the Organization).
- To facilitate collaboration with other organizations dealing with related health problems.
- Develop, publish and disseminate guidelines and educational materials.
- Continue jointly with IBE and ILAE to provide the overall coordination of the GCAE.
- Represent WHO in the GCAE Secretariat.

### 6.7 Secretariat of the GCAE

Together with the WHO Regional Office for Africa co-ordinate the implementation of the GCAE.

- To co-monitor the implementation of the recommendations.
- Together with the IBE/ILAE Regional Commissions support countries in their initiatives to become chapters of the IBE or ILAE.
- To create opportunities for more representation of the African Region in ILAE and IBE Commissions.
- To create the possibility of greater participation of African delegates at international epilepsy meetings.
- To explore the possibility of purchasing AEDs at lower costs and investigate the feasibility of setting up drug banks in the Region.
- To maintain the infrastructure and operation for networking (integrating the available addresses of people dealing with epilepsy in the different countries).

## ■ **6.8 Co-ordination and implementation**

It is essential to develop appropriate strategies to ensure that the proposals contained in this report are given due consideration and that the envisaged actions are implemented. This process should include the following components:

### ■ **6.8.1 Identification of role-players**

Very few African countries presently have formal structures dedicated to working with people with epilepsy. The Report acknowledges and endorses the work of the International Bureau for Epilepsy and the International League against Epilepsy in their efforts to establish national associations as well as regional co-operatives.

The Report calls upon all roles players within WHO, IBE and ILAE to extend these efforts to identifying key people outside of these structures who have an interest in epilepsy or are well positioned to promote the interests of people with the condition. Such individuals should be offered whatever support is available through IBE and ILAE with a view to integrating these resources into their own country situations.

### ■ **6.8.2 Mandates from people with epilepsy**

Clear mandates of support from existing organizations of people with epilepsy should be sought in order to validate the Report and the efforts of the Global Campaign Against Epilepsy

### ■ **6.8.3 Co-ordination through existing structures**

The structures of IBE and ILAE, individually and collectively, are ideally positioned to play a co-ordinating role in order to ensure that the proposals of this Report are considered and, where appropriate, implemented.

### ■ **6.8.4 Capacity building and support**

The limited resources and capacity in many African countries should not become a barrier to the implementation of this Report. Existing IBE and ILAE structures have much to offer in the way of knowledge and skills transfer and should be called upon to fulfill this role in respect of neighbouring countries.

### ■ **6.8.5 Monitoring and evaluation**

In order to assess the impact of implementing the proposals of this Report and to make the necessary modifications, a process of monitoring with evaluation of clearly articulated indicators will be necessary. It is proposed that this be a multi-factorial process with countries taking responsibility for their own programmes and being invited to share their outcomes with the collective bodies with a view to developing best practice models across the continent.



## 7. Conclusion

The general economic crisis experienced by the Member States of the WHO African Region leads to a gradual decline in the provision of health services. In this socioeconomic context, noncommunicable diseases in general and mental health in particular are not prioritized in the national health policies of the majority of governments. In Africa, epilepsy is not considered as a common disease by the general population. It leads to stigmatization, rejection, and discrimination in many aspects of life. The major problem is the lack of knowledge about epilepsy and the absence of collaboration between traditional and modern approaches. Furthermore, treatment gaps are exacerbated by the lack of affordable, accessible and available care. People with epilepsy can spend years from the moment of their first seizure before they consult modern medical services and benefit from the progress achieved nowadays. As part of

new visions in health policies and sustainable development approaches there is an opportunity for patients in Africa through the actions that can be taken to dramatically reduce many secondary and preventable causes of seizures, including infectious diseases and perinatal factors. The opportunity offered by the international and collaborative initiative set up by the International Bureau for Epilepsy, the International League Against Epilepsy and the World Health Organization through the: *"Global Campaign Against Epilepsy — Epilepsy out of the Shadows"*, could progressively transform the actual epidemiological figures with the support of every African government, UN agencies, international institutions, public and private sectors, NGOs and the pharmaceutical industry. The goal is to free every African from the burden of any preventable or manageable epileptic disorder.

## 8. Annexes

### ■ Annex 1: African Declaration on Epilepsy

## AFRICAN DECLARATION ON EPILEPSY

Under the aegis of the Global Campaign Against Epilepsy of the World Health Organization (WHO), International League against Epilepsy (ILAE) and International Bureau for Epilepsy (IBE), a meeting “Epilepsy: a Healthcare priority in Africa” was held in Dakar, Senegal, Africa on 5 and 6 May 2000. Professionals from Health and Social Sciences sectors and representatives from universities coming from every African Region unanimously agreed to the following Declaration:

#### Considering that:

- epilepsy is the most common serious chronic brain disorder, estimated to affect at least 50 million people in the world of which 10 million live in Africa alone, irrespective of race, religion, sex, age or socioeconomic groups,
  - epilepsy is not an infectious disease and seizures are not contagious,
  - all people with epilepsy can be effectively and inexpensively treated,
  - ¾ of people with epilepsy in Africa have no access to healthcare provisions and are not appropriately treated,
  - general information about epilepsy, trained expertise, diagnostic facilities, antiepileptic drugs and surgery are not available to – or affordable by – the majority of people with epilepsy, for geographical, financial or cultural reasons,
  - beliefs in supernatural causes and traditional treatment of epilepsy in Africa contribute to the under-utilization of the medical health services, to discrimination and social isolation,
  - because of these factors, disability and mortality are greater in Africa than elsewhere,
  - epilepsy has serious physical, psychological and social consequences for the afflicted and their families,
  - the impact of epilepsy is most severe in children and adolescents,
- in Africa preventable causes of epilepsy are more frequent than elsewhere, including infectious diseases, head trauma, insufficient perinatal care and consanguinity,
  - epilepsy does not receive adequate attention in existing national health plans,

#### We proclaim the following:

Epilepsy is a healthcare priority in Africa requiring every government to develop a national plan to:

- ⇒ address the needs with respect to epilepsy in terms of access to trained personnel, modern diagnostic equipment, antiepileptic medication and surgical treatment, information communication, prevention and social integration,
- ⇒ educate and train health care and other relevant professionals about epilepsy,
- ⇒ educate those affected by epilepsy and the general public about epilepsy as a universal neurological, noncommunicable and treatable condition,
- ⇒ eliminate discrimination in all spheres of life, particularly at school and the work place,
- ⇒ encourage incorporation of prevention and treatment of epilepsy in national plans for other relevant healthcare issues such as maternal and child health, mental health, infections, head trauma, neurovascular diseases and community based rehabilitation programs,
- ⇒ encourage the public and private sectors and NGO's to get involved in the local activities of the Global Campaign against Epilepsy,
- ⇒ promote interaction with traditional health systems,
- ⇒ encourage basic and applied research on epilepsy,
- ⇒ proclaim a National Epilepsy Day,
- ⇒ encourage regional and continental cooperation.

DAKAR, 6th May 2000

## Annex 2: Tables

Table 1: General health personnel

Country	Population	Physicians		Nurses and Midwives	
		Number	Per 100.000	Number	Per 100.000
Algeria	30.291.000	25.747	85	90.207	297,8
Angola	13.134.000	1.051	8	15.038	114,5
Benin	6.272.000	376	6	1.279	20,4
Botswana	1.541.000	370	24	3.376	219,1
Burkina Faso	11.535.000	346	3	2.261	19,6
Burundi	6.356.000	191	3	0	
Cameroon	14.876.000	1.041	7	5.459	36,7
Cape Verde	427.000	73	17	237	55,6
Central African Rep.	3.717.000	149	4	327	8,8
Chad	7.885.000	237	3	1.159	14,7
Comores	706.000	49	7	241	34,1
Congo Dem. Rep.	50.948.000	3.566	7	94.305	185,1
Cote d'Ivoire	16.013.000	1.441	9	4.996	31,2
D.R. Congo	3.018.000	755	25	0	
Euatorial Guinea	457.000	114	25	181	39,5
Eritrea	3.659.000	110	3	585	16
Ethiopia	62.908.000	10.694	17	0	
Gabon	1.230.000	234	19	0	
Gambia	1.303.000	52	4	163	12,5
Ghana	19.306.000	1.158	6	13.900	72
Guinea	8.154.000	1.060	13	4.542	55,7
Guinea-Bissau	1.199.000	204	17	1.312	109,4
Kenya	30.669.000	3.987	13	27.633	90,1
Lesotho	2.035.000	102	5	1.223	60,1
Liberia	2.913.000	58	2	125	4,3
Madagascar	15.970.000	1.757	11	3.450	21,6
Malawi	11.308.000	905	8	0	
Mali	11.351.000	568	5	1.487	13,1
Mauritania	2.665.000	373	14	1.663	62,4
Mauritius	1.161.000	987	85	2.704	232,9
Mozambique	18.292.000	549	3	0	
Namibia	1.757.000	70	4	2.952	168
Niger	10.832.000	433	4	2.481	22,9
Nigeria	113.862.000	20.495	18	75.263	66,1
Rwanda	7.609.000	609	8	0	
Sao Tome Principe	138.000	65	47	176	127,4
Senegal	9.421.000	754	8	2.082	22,1
Seychelles	80.000	106	132	374	467,6
Sierra Leone	4.405.000	308	7	1.454	33
South Africa	43.309.000	24.253	56	204.332	471,8
Swaziland	925.000	139	15	0	
Tanzania	35.119.000	1.405	4	0	
Togo	4.527.000	362	8	1.345	29,7
Uganda	23.300.000	3.262	14	4.357	18,7
Zambia	10.421.000	729	7	11.786	113,1
Zimbabwe	12.627.000	1.768	14	16.251	128,7
<b>Total</b>	<b>639.631.000</b>	<b>113.060</b>		<b>600.705</b>	

Adapted from Questionnaires on Country Resources for Epilepsy

**Table 2: Incidence studies in the African Region**

Country	Authors	Year	Population size	Incidence (per 100 000)
<b>Controlled and published studies</b>				
<b>Burkina Faso</b>	Debouverie et al.	1993	16 627	83
<b>Ethiopia</b>	Tekle-Haimanot et al.	1997	61 686	64
<b>Tanzania</b>	Rwiza et al.	1993	16 635	73
<b>Togo</b>	Grunitzky et al.	1991	19 241	119
<b>Uganda</b>	Kaiser et al.	1998	4 389	156
<b>Unpublished reported data</b>				
<b>Algeria</b>	Mait-Kaci	1978	30 000	56

*See references*

Table 3: Prevalence studies in the African Region

Country	Authors	Year	Population size	Prevalence (per 1000)	Area	Criteria	Method
Algeria	Mait-Kaci	1978	1.998.000	5.6	R/U	?	?
Benin*	Gbenou	1995	530	24.5	R	+	CS
Benin	Avode et al.	1996	1 443	15.2	R	+	CS
Burkina Faso	Debouverie et al.	1993	16 627	10.6	R	+	CS
Cameroon*	Nkwi, Ndongko	1989	72 647	11.0	R	-	MF
Cameroon	Nkwi, Ndongko	1989	500	58	R	-	CS
Cameroon	Dongmo et al.	1998	1 900	58.0	R	+	CS
Congo	Petitjean et al.	1995	1 000	20.0	R	-	GP
Congo	Petitjean et al.	1995	7 000	3.5	R	+	GP
Cote d'Ivoire	Giordano	1976	14 784	6.5	R	-	GP
Cote d'Ivoire	Kouassi	1988	1 176	7.6	R	+	CS
Cote d'Ivoire*	Kouadjo	1990	309	74.0	R	+	CS
Cote d'Ivoire*	Kaudjhis	1995	920	59.0	R	+	CS
Ethiopia*	Giel	1970	370	8.0	R	-	GP
Ethiopia*	Giel	1970	384	5.0	U	-	GP
Ethiopia	Zenebe Gedlie Damtie	2001	71 442	14.2	R	+	CS
Ethiopia	Tekle-Haimanot et al.	1990	60 820	5.2	R	+	CS
Ghana	Haddock	1967	3 912	3.3	R	-	GP
Kenya	Kaamugisha et al.	1988	2 960	18.2	R	+	CS
Liberia	Gerrits	1983	4 406	49.0	R	+	GP
Liberia	Goudsmit et al.	1983	4 436	28.0	R	+	CS
Malawi	Watts	1992	90 000	5.2	U	-	MF
Mali	Farnarier et al.	2000	5 243	15.6	R	+	CS
Mali	Traore et al.	2000	4 074	11.3	U	+	CS
Nigeria	Dada	1970	2 592	3.1	U	-	GP
Nigeria	Izuora, Azubuik	1977	2 288	14.0	U	-	MF
Nigeria*	Osuntokun et al.	1982	903	37.0	R	+	CS
Nigeria	Osuntokun et al.	1987	18 954	5.3	U	+	CS
Nigeria	Longe, Osuntokun	1989	2 925	6.2	R	+	CS
Rwanda	Piroux	1960	15 000	4.5	R	-	GP
Senegal	Ndiaye et al.	1986	7 682	8.3	R	+	CS
Senegal	Diop et al.	1996	2 803	21.0	R	+	CS
South Africa	Hurst et al.	1961	50 000	2.2	R	+	MF
South Africa	Bird et al.	1962	376 000	3.7	R	-	MF
Swaziland	Reis	1994	8 800	11.0	R	+	GP
Tanzania	Jilek,-Aall	1970	10 000	20.1	R	+	MF
Tanzania	Rwiza	1992	18 183	10.2	R	+	CS
Tanzania	Rwiza	1994	20 284	35,8	R	+	CS
Togo	Dumas et al.	1989	5 264	16.7	R	+	CS
Togo	Grunitzky et al.	1991	19 241	12.3	R	+	CS
Togo	Grunitzky et al.	1996	4 182	13.1	R	+	CS
Togo	Balogou et al.	2000	9 143	18.6	R	+	CS
Uganda	Orley	1970	13 174	2.1	R	-	MF
Uganda	Kaiser et al.	1996	4 743	13.0	R	+	CS
Zimbabwe	Levy et al.	1961	17 500	7.4	R	-	GP

Druet-Cabanac, 2002

\*Studies performed on population size under 1,000. **GP**: General Population. **CS**: Cross-sectional. **MF**: Medical Files. **U**: Urban. **R**: Rural. **Criteria**: Epilepsy defined as "recurrent, unprovoked seizures": (+) = yes; (-) = no.

Table 4: Neuroscience personnel, means of diagnostic and NGO's

Country	Neuro- logists	Neuro- surgeons	Psychia- trists	EEG	CT-Scan	MRI	NGO against Epilepsy	
							Professionnel	Social
Algeria	80	30	30	50	30	6	LACE	AEME
Angola	3	3	2	4	3	0	0	0
Benin	4	0	14	2	2	0	ABLE	ABLE
Botswana	0	0	0	1	1	0	0	0
Burkina Faso	2	2	7	2	1	0	L.Burkin.C.E.	0
Burundi	2	0	1	1	0	0		0
Cameroon	4	2	3	3	2	0	ANALEC	ERAC
Cape Verde	0	0	0	0	0	0	0	0
Cent. Afr. R.	2	0	2	1	0	0	0	0
Chad	0	1	1	0	0	0	0	0
Comoros	1	0	0	0	0	0	0	0
Congo	3	1	2	2	1	0	SCLE	0
D.R. Congo	25	1	25	2	1	0	LCCE	0
Côte d'Ivoire	9	7	40	7	3	0	0	0
Equ. Guinea	0	0	1	0	0	0	0	0
Eritrea	0	0	1	0	1	1	0	0
Ethiopia	4	3	10	4	3	0	0	ESAE
Gabon	4	1	4	4	2	1	0	0
Gambia	0	0	2	1	0	0	0	0
Ghana	3	5	0	1	1	0	0	GEA
Guinea	3	2	8	1	0	0	0	BVE
Guinea-Bis.	0	0	0	0	0	0	0	0
Kenya	11	7	30	10	11	2	KSE	KAWE
Lesotho	0	0	2	0	1	0	0	0
Liberia	0	0	0	0	0	0	0	0
Madagascar	5	2	12	4	1	0	0	AMAEE
Malawi	0	0	0	0	0	0	0	0
Mali	3	2	5	1	1	0	0	0
Mauritania	2	2	4	2	1	0	LMCE	0
Mauritius	2	0	1	1	1	0	0	0
Mozambique	0	1	1	1	1	0	0	0
Namibia	0	0	0	0	1	0	0	0
Niger	1	1	4	1	0	0	0	0
Nigeria	10	0	0	0	0	0	EAN	0
Rwanda	1	1	1	2	1	1	0	0
SaoTome Pr.	0	0	1	0	0	0	0	0
Senegal	9	5	12	5	5	0	LSCE	LSCE
Seychelles	0	0	0	0	0	0	0	0
Sierra Leone	0	0	0	0	0	0	0	0
South Africa	111	12	474	60	214	46	0	ESAU
Swaziland	0	0	1	0	0	0	0	0
Tanzania	2	5	10	2	5	0	TEA	POCET
Togo	5	1	4	4	2	0	ATCE	0
Uganda	6	2	9	4	2	0	0	ESA
Zambia	2	0	10	1	3	1	0	EAZ
Zimbabwe	1	5	10	5	9	3	ZLAE	ESFZ

Adapted from Questionnaires on Country Resources for Epilepsy

**ABLE:** Association Béninoise Contre l'Epilepsie. **AEME:** Association d'Entraide aux Malades Epileptiques. **AMAEE:** Association Malgache d'Aide et d'Entraide aux Epileptiques. **ANALEC:** Association Nationale de Lutte Contre l'Epilepsie au Cameroun. **ATCE:** Association Togolaise Contre l'Epilepsie. **BVE:** Bien Vivre avec l'Epilepsie. **EAN:** Epilepsy Association of Nigeria. **ERAC:** Epilepsy Research and Action Centre. **ESA:** Epilepsy South Africa. **ESAU:** Epilepsy Support Association Uganda. **ESAE:** Epilepsy Support Association of Ethiopia. **EAZ:** Epilepsy Association of Zambia. **ESFZ:** Epilepsy Support Foundation of Zimbabwe. **ESSA:** Epilepsy Society of South Africa. **GEA:** Ghana Epilepsy Association. **KAWE:** Kenya Association for the Welfare of Epileptics. **KSE:** Kenya Society for Epilepsy. **LACE:** Ligue Algérienne Contre l'Epilepsie. **LBCE:** Ligue Burkinabé Contre l'Epilepsie. **LCCE:** Ligue Congolaise Contre l'Epilepsie. **LMCE:** Ligue Mauritanienne Contre l'Epilepsie. **LSCE:** Ligue Sénégalaise Contre l'Epilepsie. **POCET:** Parents Of Children With Epilepsy in Tanzania. **SCLE:** Société Congolaise de Lutte contre l'Epilepsie. **TEA:** Tanzania Epilepsy Association. **ZLAE:** Zimbabwe League Against Epilepsy

**Table 5: main available AEDs and costs**

This table is based upon information from the Atlas MH resources 2001 of WHO.

For each country the calculation is of the amount of tablets in the commonest available strength of each AED needed to treat one patient for one year with a Defined Daily Dose (DDD) and the cost of this treatment in US\$. The DDD is the estimated average effective dose per day for a drug used in its main indications. The DDD is assigned by the WHO Collaborating Centre for Drugs Statistics Methodology and Nordic Council on Medicines.

Def.Daily.Dose	phenobarb 100 mg	phenytoin 300 mg	Valproate 1500 mg	Carbamazepine 1000 mg	Diazepam for children 15 mg?
Algeria	400 à 100 mg	1100 à 100 mg	1100 à 500 mg	1900 à 200 mg	2800 à 2 mg
Angola	400 à 100 mg	1100 à 100 mg	not available	1900 à 200 mg	1100 à 5 mg
Benin	strength ?	strength ?	strength ?	1900 à 200 mg	strength ?
Botswana	1250 à 30 mg	1100 à 100 mg	1900 à 300 mg	1900 à 200 mg	1100 à 5 mg
Burkina Faso	400 à 100 mg	not available	not available	1900 à 200 mg	1100 à 5 mg
Burundi	400 à 100 mg	1100 à 100 mg	1100 à 500 mg	3700 à 100 mg	1100 à 5 mg
Cameroon	400 à 100 mg	1100 à 100 mg	2800 à 200 mg	1900 à 200 mg	1100 à 5 mg
Cape Verde	400 à 100 mg	1100 à 100 mg	2800 à 200 mg	1900 à 200 mg	1100 à 5 mg
Central African Rep.					
Republic	400 à 100 mg	not available	not available	not available	550 à 10 mg
Chad	800 à 50 mg	not available	not available	1900 à 200 mg	1100 à 5 mg
Comoros	800 à 50 mg	not available	not available	not available	1100 à 5 mg
Congo	400 à 100 mg	?	not available	?	1100 à 5 mg
Dem. Rep. Congo	400 à 100 mg	\$0,96	not available	1900 à 200 mg	550 à 10 mg
Cote d'Ivoire					
(Ivory Coast)	3700 à 10 mg	?	?	1900 à 200 mg	1100 à 5 mg
Equatorial Guinea	1250 à 30 mg	not available	not available	950 à 400 mg	1100 à 5 mg
Eritrea	1250 à 30 mg	\$40,00	not available	33.177,75	1100 à 5 mg
Ethiopia	400 à 100 mg	\$13,75	2800 à 200 mg	not available	1100 à 5 mg
Gabon	400 à 100 mg	\$2,80	not available	1900 à 200 mg	2800 à 2 mg
Gambia	400 à 100 mg	?	not available	1900 à 200 mg	not available
Ghana	1250 à 30 mg	?	not available	1900 à 200 mg	1100 à 5 mg
Guinea-Bissau	400 à 100 mg	\$34,13	not available	1900 à 200 mg	1100 à 5 mg
Guinée (Conakry)	Available.	?	Available.	1900 à 200 mg	1100 à 5 mg
	Strength not given	Strength not given	Strength not given	Strength not given	1100 à 5 mg
Guinea Equatorial					
see Equatorial Guinea					
Kenya	1250 à 30 mg	?	not available	1900 à 200 mg	1100 à 5 mg
Lesotho	1250 à 30 mg	\$1,50	2800 à 200 mg	1900 à 200 mg	550 à 10 mg
Liberia	400 à 100 mg	?	not available	not available	2800 à 2 mg
Madagascar	800 à 50 mg	\$5,92	1100 à 500 mg	1900 à 200 mg	1100 à 5 mg
Malawi	1250 à 30 mg	\$33,75	not available	1900 à 200 mg	1100 à 5 mg
Malawi	400 à 100 mg	\$40,00	not available	1900 à 200 mg	550 à 10 mg
Mali	400 à 100 mg	\$40,00	1100 à 500 mg	1900 à 200 mg	550 à 10 mg
Mauritania	400 à 100 mg	\$11,68	1100 à 500 mg	1900 à 200 mg	550 à 10 mg
Mauritius	1250 à 30 mg	\$1,88	2800 à 200 mg	1900 à 200 mg	2800 à 2 mg
Mozambique	400 à 100 mg	\$1,52	1100 à 100 mg	1900 à 200 mg	2800 à 2 mg
Namibia	1250 à 30 mg	\$2,38	5500 à 100 mg	1900 à 200 mg	550 à 10 mg
Niger	800 à 50 mg	\$40,00	?	1900 à 200 mg	1100 à 5 mg
Nigeria	1250 à 30 mg	\$9,38	not available	not available	550 à 10 mg
Rwanda	Strength not given	?	2800 à 200 mg	1900 à 200 mg	1100 à 5 mg
	Strength not given	Strength not given	Strength not given	Strength not given	Available.
Sao Tome Principe	400 à 100 mg	\$8,00	not available	not available	550 à 10 mg
Senegal	400 à 100 mg	\$5,48	1100 à 500 mg	1900 à 200 mg	1100 à 5 mg
Seychelles	1250 à 30 mg	\$15,00	2800 à 200 mg	1900 à 200 mg	1100 à 5 mg
Sierra Leone	610 à 60 mg	\$30,50	not available	not available	550 à 10 mg
South Africa	1250 à 30 mg	\$3,00	2800 à 200 mg	1900 à 200 mg	1100 à 5 mg
Swaziland	1250 à 30 mg	\$2,50	not available	1900 à 200 mg	1100 à 5 mg
Tanzania	1250 à 30 mg	\$1,50	not available	not available	not reported
Tchad see Chad					
Togo	400 à 100 mg	\$37,32	2800 à 200 mg	1900 à 200 mg	1100 à 5 mg
Uganda	1250 à 30 mg	\$4,13	not available	not available	1100 à 5 mg
Zambia	1250 à 30 mg	\$11,25	2800 à 200 mg	1900 à 200 mg	2800 à 2 mg
Zimbabwe	210 à 180 mg	\$0,95	not available	920 à 400 mg	1100 à 5 mg
		\$11,00			\$3,96

Atlas Country Profiles on Mental Health Resources 2001 WHO Geneva

## ■ Annex 3: Country data from the African Region

### ALGERIA\*

Area: 2 381 745 km<sup>2</sup>. General Population: 30.3 million (mn). Projected Population by 2030: 48 mn. Rural Population: 40% of total. Lower middle-income country. Public Health Exp: 3.1% of GDP. Life Expectancy at Birth: 70 yrs. Under-5 mortality: 71 per 1000 children. Access to safe water: 98% of urban pop. Access to sanitation: 94% of urban pop. Prevalence of HIV: 0.07% of adults. Female Youth Illiteracy: 56%. Male Youth Illiteracy: 24%. There are 80 Neurologists, 30 Neurosurgeons and 30 Psychiatrists. There are 50 EEG machines, 30 CT scanners, 6 MRI, 1 SPECT unit. The country has a Ligue Algérienne contre l'Epilepsie (ILAE chapter), and an Association d'Entraide aux Malades Epileptiques (Espoir) (IBE chapter). Major causes of seizures are perinatal factors, head trauma, idiopathic, vascular disorders and post-infections. The available antiepileptic drugs are: Phenobarbital (150 Dinars/box), Phenytoin (200 DA/box), Carbamazepine (400 DA/box), Benzodiazepine (100 DA/box) and Valproate (600 DA/box).

### ANGOLA\*

Area: 1 246 700 km<sup>2</sup>. Population: 13.1 million (mn). Projected Population by 2030: 27 mn. Rural Population: 66% of total. Low income-country. Public Health Exp: 3.6% of GDP. Life Expectancy at Birth: 45 yrs. Under-5 mortality: 204 per 1000 children. Access to safe water: 38% of urban pop. Access to sanitation: 44% of urban pop. Prevalence of HIV: 2.78% of adults. Female Youth Illiteracy: 71%. Male Youth Illiteracy: 43%. There are 3 Neurologists, 3 Neurosurgeons and 2 Psychiatrists. There are 4 EEG machines, 3 CT Scanners and no MRI. Major causes of seizures are drug consumption, head trauma, perinatal factors and infections. There is no IBE or ILAE chapter. Epilepsy is not yet included in the National Mental Health Programme. The available antiepileptic drugs are Phenobarbital, Phenytoin, Carbamazepine, Benzodiazepines and Valproate.

\*Countries having completed the Questionnaire on Country Resources for Epilepsy. Cost and presentation of AEDs are indicated as given in the Questionnaire by the responding country. A standardized presentation is reported in Table 5.

### BENIN

Area: 112 620 km<sup>2</sup>. Population: 6.2 million (mn). Life Expectancy: 49. Projected Population by 2030: 12 mn. Rural Population: 59% of total. Low-income country. Public Health Exp: 3.0% of GDP. Life Expectancy at Birth: 55 yrs. Under-5 mortality: 140 per 1000 children. Access to safe water: 63% of urban pop. Access to sanitation: 23% of urban pop. Prevalence of HIV: 2.45% of adults. Female Youth Illiteracy: 68%. Male Youth Illiteracy: 40%. Benin has 4 Neurologists; 14 Psychiatrists and an Association Beninoise de Lutte contre l'Epilepsie (A.B.L.E. ILAE chapter). There are 2 CT scanners and 2 EEG machines.

### BOTSWANA\*

Area: 600 370 km<sup>2</sup>. Population: 1.5 million (mn). Projected population by 2030: 2 mn. Rural Population: 50% of total. Higher middle-income country. Public Health Exp: 4.2% of GDP. Life Expectancy at Birth: 40 yrs. Under-5 mortality: 105 per 1000 children. Access to sanitation: 31% of urban pop. Access to water: 88% of urban pop. Prevalence of HIV: 35.80% of adults. Female Youth Illiteracy: 27%. Male Youth Illiteracy: 22%. There is no Neurologist, no Psychiatrist and no Neurosurgeon. There is 1 EEG machine, 1CT Scanner and no MRI. There is no IBE or ILAE chapter. Major causes of seizures are idiopathic, head trauma, alcoholic, perinatal factors and inherited. The available antiepileptic drugs are free of charge because they are provided by the government: Phenobarbital, Phenytoin, Carbamazepine, Benzodiazepines and Valproate.

### BURKINA FASO\*

Area: 274 200 km<sup>2</sup>. Population: 11.5 million (mn). Projected Population by 2030: 22 mn. Rural Population: 82% of total. Low-income country. Public Health Exp: 4.2% of GDP. Life Expectancy at Birth: 47 yrs. Under-5 Infant mortality: 169 per 1,000 births. Access to safe water: 24% of urban pop. Access to sanitation: 29% of urban pop. Prevalence of HIV: 6.4% of adults. Female Youth Illiteracy: 71%. Male Youth Illiteracy: 68%. There are 2 Neurologists, 7 Psychiatrists and 2 Neurosurgeons. There are 2 EEG machines, 1 CT Scanner and no MRI. Major causes of seizures are perinatal factors, infections including cysticercosis,



meningo-encephalitis, febrile convulsions, head trauma and vascular disorders. Available antiepileptic drugs: Phenobarbital (7.3 francs cfa/tablet), Carbamazepine (108 fcfa/tablet) and Valproate (240 fcfa/tablet). An ILAE chapter exists since 1992.

#### **BURUNDI\***

Area: 27 830 km<sup>2</sup>. Population: 6.4 million (mn). Life Expectancy at Birth: 41. Rural Population: 48% of total. Low- income country. Public Health Exp: 4% of GDP. Under-5 mortality: 196 per 1000 children. Access to safe water: 60% of urban pop. Access to sanitation: 43% of urban pop. Prevalence of HIV: 11.32% of adults. Female Youth Illiteracy: 53%. Male Youth Illiteracy: 43%. There is no IBE or ILAE chapter. There are 2 Neurologists, 1 Psychiatrist and no Neurosurgeon. 1 EEG machine is available. There are no CT Scanners and MRI. Major causes of seizures are perinatal factors, infections including cysticercosis, meningo-encephalitis, and febrile convulsions. The available antiepileptic drugs are: Phenobarbital (260 Francs Burundi/box), Carbamazepine (8 000 FB/box), Benzodiazepine and Valproate (11000 FB/box).

#### **CAMEROON\***

Area: 475 500 km<sup>2</sup>. Population: 14.8 million (mn). Population Density: 2.10 per km<sup>2</sup>. Projected Population by 2030: 26 mn. Rural Population: 1.30% of total. Low-income country. Public Health Exp: 5% of GDP. Life Expectancy at Birth: 50 yrs. Under-5 mortality: 150 per 1000 children. Access to Sanitation: 92% of urban pop. Access to water: 62% of urban pop. Prevalence of HIV: 7.73% of adults. Female Youth Illiteracy: 37%, Male Youth Illiteracy: 19%. A professional Association Nationale de Lutte contre l'épilepsie au Cameroun (ILAE chapter) and an IBE Friend (Epilepsy Research & Action Center). There are 4 Neurologists, 3 Psychiatrists and 2 Neurosurgeons. There are 3 EEG machines, 2 CT Scanners and no MRI. Major causes of seizures are perinatal factors, cysticercosis and other infections, genetic, head trauma and vascular disorders. The available antiepileptic drugs are: Phenobarbital (75 Francs cfa/tablet), Phenytoin (30 fcfa/tablet), Carbamazepine (170 Fcfa/tablet), 53 fcfa/tablet, and Valproate (226 Fcfa/tablet).

#### **CAPE VERDE\***

Area: 4030 km<sup>2</sup>. Population: 427 000. Life Expectancy

at Birth: 69. Under-5 mortality: 67 per 1000 children. Lower middle- income country. Access to sanitation: 71% of urban pop. Access to water: 74% of urban pop. Female Youth Illiteracy: 35%, Male Youth Illiteracy: 27%. There are no Neurologists, no Neurosurgeon, no Psychiatrist. People with epilepsy can consult the paediatric department, the department of general medicine or the psychiatric department. There are no EEG machines, CT Scanners or MRI. There is no IBE or ILAE chapter. Major causes of seizures are perinatal factors, head trauma, cysticercosis and other infections. Epilepsy is included in the National Mental Health Programme. For epilepsy the drug most often prescribed is carbamazepine. As an alternative valproate is named, but this drug is far less used because of the price difference. There are often interruptions in the availability of antiepileptic drugs. The costs of available antiepileptic drugs are: Phenobarbital (0.7 ecv/unit), Phenytoin (5.8 ecv/unit), Carbamazepine (5.1 ecv/unit), Clonazepam, and Valproate (22.2 ecv/unit).

#### **CENTRAL AFRICAN REPUBLIC\***

Area: 622 980 km<sup>2</sup>. Population: 3.7 million (mn). Projected Population by 2030: 48 mn. Rural Population: 59% of total. Low-income country. Public Health Exp: 2.9% of GDP. Life Expectancy at Birth: 44 yrs. Under-5 mortality: 162 per 1000 children. Access to safe water: 61% of urban pop. Access to sanitation: 30% of urban pop. Prevalence of HIV: 13.84% of adults. Female Youth Illiteracy: 69%, Male Youth Illiteracy: 43%. There is no IBE or ILAE chapter. There are 2 Neurologists, 2 Psychiatrists and no Neurosurgeon. There is 1 EEG machine but no CT Scanner or MRI. Major causes of seizures are alcoholism, perinatal factors, head trauma, cysticercosis and other infections. The available antiepileptic drugs are: Phenobarbital (10 Francs cfa/tablet), Carbamazepine (120 Fcfa/tablet), Diazepam (5 fcfa/tablet), Clonazepam (93 fcfa/tablet) and Valproate (367 Fcfa/tablet).

#### **CHAD\***

Area: 1 284 000 km<sup>2</sup>. Population: 7.8 million (mn). Projected by 2030: 16 mn. Rural Population: 77% of total. Low-income country. Public Health Exp: 4.3% of GDP. Life Expectancy at Birth: 46 yrs. Under-5 mortality: 172/1000 children. Access to sanitation: 29%. Access to water: 27% of urban

pop. HIV: 2.69% of adults. Female Youth Illiteracy: 65%, Male: 38%. There is an "Association for the promotion of mental health". There is 1 Psychiatrist and 1 Neurosurgeon. No EEG machine and no CT Scanner. Major causes of seizures: infection, head trauma and cysticercosis. Drugs are represented by Phenobarbital and Carbamazepine.

### COMOROS

Area: 2170 km<sup>2</sup>. Population: 706 000. Under-5 mortality rate: 142 per 1000 births. Access to sanitation: 40% of urban pop. Prevalence of HIV: 0.12% of adults. Low-income country. Public health Exp: 4.5 of GDP. Access to safe water: 96% of urban pop. Access to sanitation: 98% of urban pop. Life Expectancy at birth: 59 yrs. Female Youth Illiteracy: 49%, Male Youth Illiteracy: 35%. There is 1 Neurologist, but no neurosurgeon, psychiatrist and no brain diagnostics tools. There is no IBE or ILAE chapter.

### REP. OF CONGO\*

Area: 342 000 km<sup>2</sup>. Population: 3.1 million (mn). Projected Population by 2030: 6 mn. Rural Population: 38% of total. Low-income country. Health Exp: 5% of GDP. Life Expectancy at Birth: 51 yrs. Infant mortality: 90 per 1000 births. Access to sanitation: 92% of urban pop. Access to water: 51% of urban pop. Prevalence of HIV: 6.43% of adults. Female Youth Illiteracy: 29%, Male Youth Illiteracy: 15%. A "Société Congolaise Contre l'Epilepsie" (ILAE chapter) has been founded. There are 3 Neurologists, 2 Psychiatrists and 1 Neurosurgeon. There are 2 EEG machines, 1 CT Scanner and no MRI. Major causes of seizures are perinatal factors, head trauma, and infections with many HIV cases. The available antiepileptic drugs are: Phenobarbital (2000 Francs cfa/box), Carbamazepine (6000 Fcfa/box), Clonazepam (2000 fcfa/box) and Valproate (8000 Fcfa/box).

### DEMOCRATIC REPUBLIC OF CONGO\*

Area: 2 345 410 s km<sup>2</sup>. Population: 50.9 million (mn). Projected Population by 2030: 114 mn. Rural Population: 70% of total. Low-income country. Public Health Exp: 3.7% of GDP. Life Expectancy at Birth: 51 yrs. Under-5 mortality: 141 per 1000 children. Access to safe water: 45% of urban pop. Access to sanitation: 20% of urban pop. Prevalence of HIV: 5.07% of adults. Female Youth

Illiteracy: 43%, Male Youth Illiteracy: 17%. There are 25 Neurologists, 1 Neurosurgeon and 25 Psychiatrists. There are 2 EEG machines, 1 CT Scanner and no MRI. Major causes of seizures are perinatal factors, head trauma and infections and idiopathic. A National League Against Epilepsy (ILAE chapter) exists. Available antiepileptic drugs: Phenobarbital (622 Francs cfa/box), Phenytoin (876 Fcfa/box), Carbamazepine (2239 Fcfa/box), Diazepam and Valproate (3462 Fcfa/box).

### COTE d'IVOIRE\*

Area: 322 465 km<sup>2</sup>. Population: 16.1 million (mn). Projected Population by 2030: 23 mn. Rural Population: 29.7% of total. Low-income country. Public Health Exp: 3.2% of GDP. Life Expectancy at Birth: 47 yrs. Under-5 mortality: 143 per 1000 children. Access to sanitation: 59% of urban pop. Access to water: 77% of urban pop. Prevalence of HIV: 10.76% of adults. Female Youth Illiteracy: 46%, Male Youth Illiteracy: 33%. There are 9 Neurologists, 7 Neurosurgeons, 30 Psychiatrists and 4 Pediatric Psychiatrists. There are 7 EEG machines and 3 CT Scanners. Major causes of epileptic seizures are: infections, perinatal factors, head trauma, alcoholism and idiopathic. There is no IBE or ILAE chapter. The available antiepileptic drugs are: Phenobarbital (55 Francs cfa/unit), Carbamazepine (149 F/unit), Valproate (245 F/unit) and Diazepam.

### ERITREA\*

Area: 121 000 km<sup>2</sup>. Population: 3.6 million (mn). Projected Population by 2030: 7 mn. Rural Population: 82% of total. Low-income country. Public Health Exp: 3.4% of GDP. Life Expectancy at Birth: 52 yrs. Under-5 mortality: 90 per 1000 children. Access to safe water: 46% of urban pop. Access to sanitation: 13% of urban pop. Prevalence of HIV: 2.87% of adults. There is no IBE or ILAE chapter. There is 1 Psychiatrist, no Neurologist and no Neurosurgeons. There is no EEG machine, but there is 1 CT Scanner and 1 MRI. Major causes of seizures are perinatal factors, head injury, infections, and idiopathic. The available antiepileptic drugs are: Phenobarbital, Phenytoin, Carbamazepine, Clonazepam and Valproic Acid.

### ETHIOPIA\*

Area: 1 221 900 km<sup>2</sup>. Population: 62.9 million

(mn). Projected Population by 2030: 114 mn. Rural Population: 83% of total. Low-income country. Public Health Exp: 3.8% of GDP. Life Expectancy at Birth: 44 yrs. Infant mortality: 107 per 1000 births. Access to safe water: 24% of urban pop. Access to sanitation: 15% of urban pop. Prevalence of HIV: 10.63% of adults. Female Youth Illiteracy: 69%, Male Youth Illiteracy: 47%. A comprehensive epilepsy education project was launched under the aegis of the GCAE. There are 4 Neurologists, 3 Neurosurgeons and 10 Psychiatrists. There are 4 EEG machines and 3 CT Scanners. There is an "Epilepsy Support Association of Ethiopia" (IBE chapter).

#### **EQUATORIAL GUINEA \***

Area: 28 050 km<sup>2</sup>. Population: 457 000. Life Expectancy at birth: 51 yrs. Lower middle-income country. Health Exp: 3.5% of GDP. Infant mortality: 108 per 1000 births. Access to sanitation: 53% of urban pop. Access to water: 43% of urban pop. Prevalence of HIV: 0.51% of adults. Female Youth Illiteracy: 28%, Male Youth Illiteracy: 8%. There is 1 Psychiatrist, no Neurologist and no Neurosurgeon. There are no EEG machines, CT Scanners or MRI. Major causes of seizures are perinatal factors, head trauma, infections, and idiopathic. The only available antiepileptic drugs are: Phenobarbital (10 francs cfa/tablet) and injectable Diazepam. There is no IBE or ILAE chapter.

#### **GABON\***

Area: 267 670 km<sup>2</sup>. Population: 1.2 million (mn). Projected Population by 2030: 2 mn. Rural Population: 20% of total. Higher middle income-country. Public Health Exp: 3% of GDP. Life Expectancy at Birth: 53 yrs. Under-5 mortality: 132 per 1000 children. Access to sanitation: 79% of urban pop. Access to water: 70% of urban pop. Female Youth Illiteracy: 47%, Male Youth Illiteracy: 26%. Prevalence of HIV: 1.16% of adults. There are 4 Neurologists, 1 Neurosurgeon and 4 Psychiatrists. There are 4 EEG machines, 2 CT Scanners and 1 MRI. Major causes of seizures are perinatal factors, head injury, infections including strongly HIV, Vascular disorders and idiopathic. There is no IBE or ILAE chapter. Available antiepileptic drugs: Phenobarbital (1450 Francs cfa/box), Phenytoin (1695 Fcfa/box),

Carbamazepine (5035 Fcfa/box), Diazepam (1290 Fcfa/box) and Valproate (3580 Fcfa/box).

#### **GAMBIA\***

Area: 11 300 km<sup>2</sup>. Population: 1.3 million (mn). Projected Population by 2030: 2 mn. Rural Population: 69% of total. Low-income country. Public Health Exp: 4.5% of GDP. Life Expectancy at Birth: 46 yrs. Under- 5 mortality: 56 per 1000 children. Access to sanitation: 83% of rural pop. Access to sanitation: 34% of urban pop. Access to water: 62% of urban pop. Prevalence of HIV: 1.95% of adults. Prevalence of HIV: 13,000 infected. Female Youth Illiteracy: 73%, Male Youth Illiteracy: 58%. There is no IBE or ILAE chapter There are 2 psychiatrists, no Neurologist, no Neurosurgeon. There is 1 EEG machine, but no CT Scanner or MRI. Major causes of seizures are perinatal factors, head trauma, infections. Available antiepileptic drugs are not indicated.

#### **GHANA\***

Area: 238 540 km<sup>2</sup>. Population: 19.3 million (mn). Projected Population by 2030: 33 mn. Rural Population: 2.60% of total. Low-income country. Public Health Exp: 3.1% of GDP 1990–98. Life Expectancy at Birth: 57 yrs. Under-5 mortality: 96 per 1000 children. Access to sanitation: 63% of urban pop. Access to water: 64% of urban pop. Prevalence of HIV: 3.60% of adults. Female Youth Illiteracy: 40%, Male Youth Illiteracy: 22%. There are 3 Neurologists, 5 Neurosurgeons. 1 EEG machine and 1 CT-Scanner. The Ghana Epilepsy Association (IBE chapter) has launched the GCAE on November 2001.

#### **GUINEA-BISSAU**

Area: 36 125 km<sup>2</sup>. Population: 1.2 million (mn). Projected Population by 2030: 2 mn. Rural Population: 77% of total. Low-income country. Public Health Exp: 5.7% of GDP. Life Expectancy at Birth: 45 yrs. Under- 5 mortality: 205 per 1000 children. Access to sanitation: 47% of urban pop. Access to water: 49% of urban pop. Prevalence of HIV: 2.50% of adults. Female Youth Illiteracy: 83%, Male Youth Illiteracy: 43%. There is no Neuroscience personnel, no brain diagnostic equipment and no IBE or ILAE chapter.

#### **GUINEA\***

Area: 245 860 km<sup>2</sup>. Population: 8.1 million (mn).

Projected Population by 2030: 12 mn. Rural Population: 69% of total. Low-income country. Public Health Exp: 3.5% of GDP. Life Expectancy at Birth: 47 yrs. Under-5 mortality: 184 per 1000 children. Access to sanitation: 24% of rural pop. Access to sanitation: 58% of urban pop. Access to water: 48% of urban pop. Prevalence of HIV: 1.54% of adults. Female Youth Illiteracy: 78%, Male Youth Illiteracy: 50%. There are 3 Neurologists, 2 Neurosurgeons and 8 Psychiatrists An association BIVEP (Bien vivre avec l'épilepsie) founded in 2000 and training trainers in order to inform schools about the facts of epilepsy exists. There is 1 EEG machine and no CT scanner or MRI. Major causes of seizures are perinatal factors, head injury, infections, tumours and neuro-malaria. The available antiepileptic drugs are: Phenobarbital (300 francs G/unit), Carbamazepine (340 FG/unit).

#### **KENYA\***

Area: 582 645 km<sup>2</sup>. Population: 30.6 million (mn). Projected population by 2030: 47 mn. Rural Population: 69% of total. Low-income country. Public Health Exp: 4.6% of GDP. Life Expectancy at Birth: 51 yrs. Under-5 mortality: 124 per 1000 children. Access to sanitation: 86% of urban pop. Access to water: 49% of urban pop. Prevalence of HIV: 13.95% of adults. Female Youth Illiteracy: 27%, Male Youth Illiteracy: 12%. There are 11 Neurologists, 7 Neurosurgeons and 30 Psychiatrists. Kenya has an IBE chapter, the Kenya Association for the Welfare of Epileptics, and an ILAE chapter, the Kenya Society for Epilepsy. There are 10 EEG machines, 11 CT Scanners and 2 MRI's. Major causes of seizures are perinatal factors, head injury, infections, and idiopathic. The available antiepileptic drugs are: Phenobarbital (0.3 Kenya shillings/30mg Tablet), Phenytoin (8.5 Ksh/tab), Carbamazepine (2.5 Ksh/tab), Diazepam (1.5 Ksh/tab) and Ethosuximide.

#### **LESOTHO\***

Area: 30 355 km<sup>2</sup>. Population: 2.1 million (mn). Projected Population by 2030: 3 mn. Rural Population: 74% of total. Low-income country. Public Health Exp: 5.6% of GDP. Life Expectancy at Birth: 46 yrs. Under -5 mortality: 144 per 1000 children. Access to sanitation: 92% of urban pop. Access to water: 91% of urban pop. Prevalence of

HIV: 23.57% of adults. Female Youth Illiteracy: 29%, Male Youth Illiteracy: 7%. There is no IBE or ILAE chapter. There are 2 Psychiatrists, no Neurologist and no Neurosurgeon. There is 1 CT Scanner, but no EEG machine. Main causes of seizure are: birth trauma, head injuries, infections and cerebrovascular disorders. The available antiepileptic drugs are: Phenobarbital (32.5 M/unit), Phenytoin (43.6M/unit), Carbamazepine (110.4 M/unit), Diazepam (92.4 M/unit) and Valproate (125.5 M/unit).

#### **LIBERIA**

Area: 99 067 km<sup>2</sup>. Population: 2.9 million (mn). Population Density: 31 per km<sup>2</sup>. Low-income country. Life Expectancy at birth: 47 yrs. Under-5 mortality: 187 per 1000 children. Access to sanitation: 38% of urban pop. Access to water: 49% of urban pop. Prevalence of HIV: 2.80% of adults. Female Youth Illiteracy: 78%, Male Youth Illiteracy: 46%. There is no Neuroscience personnel, no brain diagnostic equipment and no IBE or ILAE chapter.

#### **MADAGASCAR\***

Area: 587 040 km<sup>2</sup>. Population: 15.9 million (mn). Rural Population: 72% of total. Low-income country. Public Health Exp: 2.1% of GDP. Life Expectancy at Birth: 53 yrs. Under-5 mortality: 146 per 1000 children. Access to sanitation: 42% of urban pop. Access to water: 47% of urban pop. Female Youth Illiteracy: 42%, Male Youth Illiteracy: 28%. There are 5 Neurologists, 2 Neurosurgeons and 12 Psychiatrists. There are 4 EEG machines and 1 CT-Scanner. There is an ILAE chapter, the "Association Malgache d'Aide et d'Entraide aux Epileptiques". Major causes of seizures are: infections, perinatal factors, febrile convulsions, neurocysticercosis, head trauma and toxic encephalopathies. The available antiepileptic drugs are: Phenobarbital (50 Francs Malgaches (FM)/unit), Carbamazepine (25 FM/unit), Diazepam (30 FM/unit) and Valproate (64 FM/unit).

#### **MALAWI\***

Area: 118 480 km<sup>2</sup>. 10.6 million (mn). Population: 11.3. Projected Population by 2030: 20 mn. Rural Population: 78% of total. Low-income country.

Public Health Exp: 5.8% of GDP. Life Expectancy at Birth: 40 yrs. Under-5 mortality: 229 per 1000 children. Access to sanitation: 77% of urban pop. Access to water: 77% of urban pop. Prevalence of HIV: 15.96% of adults. Female Youth Illiteracy: 56%, Male Youth Illiteracy: 27%. There is no IBE or ILAE chapter. There are no Neurologists, no Neurosurgeons and no Psychiatrists. Epidemiological and etiological studies have not been performed. The only available antiepileptic drug is "Epanutin".

### **MALI**

Area: 1 240 000 km<sup>2</sup>. Population: 11.3 million (mn). Projected Population by 2030: 23 mn. Rural Population: 71% of total. Low-income country. Public Health Exp: 4.2% of GDP. Life Expectancy at Birth: 51 yrs. Under-5 mortality: 218 per 1000 children. Access to sanitation: 69% of urban pop. Access to water: 65% of urban pop. Prevalence of HIV: 2.03% of adults. Female Youth Illiteracy: 68%, Male Youth Illiteracy: 54%. There are 5 Psychiatrists, 3 Neurologists and 2 Neurosurgeons. Prevalence of epilepsy is 1.24%. There is 1 EEG machine and 1 CT scanner. There are no IBE and ILAE chapters. The Mali experience has demonstrated that when doctors go from village to village and talk to the local leaders and religious guides whose authorisations are necessary to do anything and reach families and patients, a dramatic result can be obtained.

### **MAURITANIA\***

Area: 1 030 700 km<sup>2</sup>. Population: 2.6 million (mn). Projected Population by 2030: 5 mn. Rural Population: 45% of total. Low-income country. Public Health Exp: 5.6% of GDP. Life Expectancy at Birth: 51 yrs. Under -5 mortality: 140 per 1000 children. Access to sanitation: 33% of urban pop. Access to water: 37% of urban pop. Prevalence of HIV: 0.52% of adults. Female Youth Illiteracy: 69%, Male Youth Illiteracy: 48%. There are 2 Neurologists, 2 Neurosurgeons and 4 Psychiatrists. There are 2 EEG machines. There is an ILAE but not an IBE chapter. Major causes of seizures are: infections, perinatal factors, head trauma and metabolic causes. The available antiepileptic drugs are: Phenobarbital (3 UM/unit), Carbamazepine (10 UM/unit), Diazepam (5UM/unit), Clonazepam (24 UM/unit) and Valproate (6 UM/unit).

### **MAURITIUS**

Area: 1860 km<sup>2</sup> Population 1.1 million (mn). Rural Population: 59% of total. Higher middle-income country. Public Health Exp: 3.5% of GDP. Life Expectancy at Birth: 71 yrs. Under-5 mortality: 22 per 1000 children. Access to sanitation: 99% of urban pop. Access to water: 100% of urban pop. Prevalence of HIV: 0.08% of adults. Female Youth Illiteracy: 19%, Male Youth Illiteracy: 13%. There are 2 Neurologists, 1 Psychiatrist, 1 EEG machine and 1 CT-Scanner. There is no IBE or ILAE chapter although there is an IBE Friend.

### **MOZAMBIQUE\***

Area: 801 590 km<sup>2</sup> Population: 18.3 million (mn). Projected Population by 2030: 30 mn. Rural Population: 12% of total. Low-income country. Public Health Exp: 5.8% of GDP. Life Expectancy at Birth: 39 yrs. Under-5 mortality: 213 per 1000 children. Access to sanitation: 43% of urban pop. Access to water: 60% of urban pop. Prevalence of HIV: 13.22% of adults. Female Youth Illiteracy: 64%, Male Youth Illiteracy: 60%. There is 1 Psychiatrist, no Neurologist and 1 Neurosurgeon. There is 1 EEG machine and 1 CT-Scanner. Epilepsy awareness and education programmes have been implemented. The available antiepileptic drugs are: Phenobarbital ((5,000 Mts/box of 20 tablets), Phenytoin (6,000 Mts/box of 20 tablets), Carbamazepine (21 500 Mts/box of 20 tablets), Diazepam (37 500/box of 20 tablets) and Valproate (40 200/box of 60 tablets). There is no League or Association against epilepsy.

### **NAMIBIA**

Area: 824 290 km<sup>2</sup>. Population: 1.7 million (mn). Projected Population by 2030: 3 mn. Rural Population: 70% of total. Lower middle-income country. Public Health Exp: 7.5% of GDP. Life Expectancy at Birth: 45 yrs. Under-5 mortality: 112 per 1000 children. Access to sanitation: 41% of urban pop. Access to water: 77% of urban pop. Prevalence of HIV: 19.54% of adults. Female Youth Illiteracy: 20%, Male Youth Illiteracy: 18%. There is no Neuroscience Personnel, no brain diagnostic equipment and no IBE or ILAE chapter.

### **NIGER\***

Area: 1 267 000 km<sup>2</sup>. Population: 10.8 million (mn). Projected Population by 2030: 24 mn. Rural Population: 80% of total. Low-income country. Health Exp: 3.5% of GDP. Life Expectancy at Birth: 45 yrs. Under-5 mortality: 250 per 1000 children. Access to sanitation: 20% of urban pop. Access to water: 59% of urban pop. Prevalence of HIV: 1.35% of adults. Female Youth Illiteracy: 92%, Male Youth Illiteracy: 77%. There is 1 Neurologist, 1 Neurosurgeon and 4 Psychiatrists. There is no IBE or ILAE chapter 1 EEG machine is available. Major causes of seizures are neuro-malaria, infections, encephalitis and vascular disorders. The available antiepileptic drugs are: Phenobarbital (10 Francs/unit) Phenytoin, Carbamazepine (100 francs/unit) and Diazepam.

### **NIGERIA\***

Area: 923 850 km<sup>2</sup>. Population: 113.8 million (mn). Projected Population by 2030: 255 mn. Rural Population: 58% of total. Low-income country. Public Health Exp: 3.1% of GDP. Life Expectancy at Birth: 51 yrs. Under-5 mortality: 119 per 1000 children. Access to sanitation: 57% of urban pop. Access to water: 63% of urban pop. Prevalence of HIV: 5.06% of adults. Female Youth Illiteracy: 47%, Male Youth Illiteracy: 29%. There are 11 Neurologists, 5 Neurosurgeons and 110 Psychiatrists. There are 10 EEG machines, 9 CT scanners and 1 MRI. There is a social oriented "Epilepsy Association of Nigeria". Prevalence rates range from 3.1 to 370. Major causes of seizures are: febrile convulsions, head trauma, meningo-encephalitis, perinatal causes and cerebral palsy. The available antiepileptic drugs are: Phenobarbital, Phenytoin, Carbamazepine, Diazepam, Valproate, Ethosuximide and Primidone.

### **RWANDA**

Area: 26 340 km<sup>2</sup>. Population: 7.6 million (mn). Projected Population by 2030: 15 mn. Rural Population: 94% of total. Low-income country. Public Health Exp: 4.3% of GDP. Life Expectancy at Birth: 40 yrs. Under-5 mortality: 205 per 1000 children. Access to sanitation: 38% of urban pop. Access to water: 41% of urban pop. Prevalence of HIV: 11.21% of adults. Female Youth Illiteracy: 43%, Male Youth Illiteracy: 28%. Epilepsy is part of the National Mental Health Program. There is 1 Psychiatrist, 1 Neurologist and 1 Neurosurgeon.

There are 2 EEG machines and 1 CT scanner. There are no national data on prevalence or incidence of epilepsy. There is no IBE or ILAE chapter.

### **SAO TOME AND PRINCIPE\***

Area: 960 km<sup>2</sup>. Population: 138 000. Low-income country. Public Health Exp: 4% of GDP. Life Expectancy at Birth: 65 yrs. Under-5 mortality: 64 per 1000 children. Access to sanitation: 84% of urban pop. Access to water: 79% of urban pop. Female Youth Illiteracy: 38%, Male Youth Illiteracy: 15%. There is 1 Psychiatrist, no Neurologist and no Neurosurgeon. No brain diagnosis means. Epidemiological studies have not been performed and major causes of seizures are not determined. The available antiepileptic drugs are: Phenobarbital (0.20 US\$/unit), Phenytoin (0.20 US\$/unit), Carbamazepine (0.24 US\$/unit). There is no IBE or ILAE chapter.

### **SENEGAL\***

Area: 196 190 km<sup>2</sup>. Population: 9.4 million (mn). Projected Population by 2030: 39 mn. Rural Population: 54% of total. Low-income country. Public Health Exp: 4.5% of GDP. Life Expectancy at Birth: 53 yrs. Under-5 mortality: 121 per 1000 children. Access to sanitation: 70% of urban pop. Access to water: 78% of urban pop. Prevalence of HIV: 1.77% of adults. Female Youth Illiteracy: 74%, Male Youth Illiteracy: 54%. Senegal has 9 Neurologists, 5 Neurosurgeons, 12 Psychiatrists, 5 EEG machines and 5 CT-Scanners. A League against epilepsy (IBE and ILAE chapter) exists since 1991 and provides education, training and research activities. Major causes of seizures are: idiopathic cases, post-infection, head trauma and probably genetic. Senegal is a GCAE Demonstration Project site. The available antiepileptic drugs are: Phenobarbital (1 US\$/box 100mg), Phenytoin (3 US\$/box), Carbamazepine (6 US\$/box 200mg), Diazepam (5 US\$/box 10mg) and Valproate (8.4 US\$/box 500mg).

### **SEYCHELLES**

Area: 455 km<sup>2</sup>. Population: 80 000. Infant mortality: 78 per 1000 births. Female Youth Illiteracy: 9%, Male Youth Illiteracy: 8%. High middle-income country. Life expectancy at birth: 73 yrs. Access to sanitation: 96% of urban pop. Access to water: 98% of urban pop. There is no Neuroscience Personnel and no brain diagnostic equipment. There is no IBE or ILAE chapter.

### SIERRA LEONE

Area: 71 740 km<sup>2</sup>. Population: 4.4 million (mn). Projected Population by 2030: 9 mn. Rural Population: 65% of total. Low-income country. Public Health Exp: 4.9% of GDP. Life Expectancy at Birth: 34 yrs. Under-5 mortality: 283 per 1000 children. Access to sanitation: 28% of urban pop. Access to water: 28% of urban pop. Prevalence of HIV: 2.99% of adults. Female Youth Illiteracy: 82%, Male Youth Illiteracy: 55%. There is no Neuroscience Personnel and no diagnostic equipment. There is no IBE nor an ILAE chapter.

### SOUTH AFRICA\*

Area: 1 221 040 km<sup>2</sup>. Population: 43.3 million (mn). Projected Population by 2030: 56 mn. Rural Population: 47% of total. Higher middle-income country. Public Health Exp: 7.1% of GDP. Life Expectancy at Birth: 52 yrs. Under-5 mortality: 83 per 1000 children. Access to sanitation: 86% of urban pop. Access to water: 86% of urban pop. Prevalence of HIV: 12.91% of adults. Female Youth Illiteracy: 16%, Male Youth Illiteracy: 14%. There are 111 Neurologists, 12 Neurosurgeons and 474 Psychiatrists. South Africa has an IBE ("Epilepsy South Africa") and an ILAE chapter. South Africa constitutes an exception because the treatment gap is only 20 to 25 % of the population. There are 60 EEG machines, 214 CT Scanners and 46 MRI. Major causes of seizures are idiopathic, head trauma and infections including many HIV. All the older and many of the new antiepileptic drugs are available.

### SWAZILAND\*

Area: 17 360 km<sup>2</sup>. Population: 925 000. Life Expectancy at Birth: 44 yrs. Under 5 mortality: 117 per 1000 children. Lower middle-income country. Prevalence of HIV: 25.25% of adults. Female Youth Illiteracy: 21%, Male Youth Illiteracy: 9%. Access to sanitation: 31% of urban pop. Access to water: 88% of urban pop. There is 1 Psychiatrist and no brain diagnostic equipment. There is no IBE or ILAE chapter in Swaziland. Major causes of seizures are: head trauma, congenital and unknown causes. The available antiepileptic drugs are: Phenobarbital, Clonazepam Valproate and Carbamazepine.

### TANZANIA\*

Area: 945 090 km<sup>2</sup>. Population: 35.2 million (mn). Projected Population by 2030: 56 mn.

Rural Population: 70% of total. Low-income country. Public Health Exp: 4.8% of GDP. Life Expectancy at Birth: 51 yrs. Under-5 mortality: 136 per 1000 children. Access to sanitation: 90% of urban pop. Access to water: 54% of urban pop. Prevalence of HIV: 9.42% of adults. Female Youth Illiteracy: 36%, Male Youth Illiteracy: 17%. NGO's are: the "Tanzania Epilepsy Association" and the "Parents of Children with Epilepsy in Tanzania" (IBE chapter). There are 5 Neurosurgeons, 2 Neurologists and 10 Psychiatrists. There are 2 EEG machines and 5 CT-Scanners. Major causes of seizures are: infections, poor perinatal care, head trauma and heredity. The available antiepileptic drugs are: Phenobarbital (1 Tsh/100mg), Phenytoin (90 Tsh/100mg), Carbamazepine (100 Tsh/200mg), Diazepam (400 Tsh/5mg) and Ethosuximide (150 Tsh/250mg).

### TOGO\*

Area: 56 790 km<sup>2</sup>. Population: 4.5 million (mn). Projected Population by 2030: 8 mn. Rural Population: 68% of total. Low-income country. Public Health Exp: 2.8% of GDP. Life Expectancy at Birth: 52 yrs. Under -5 mortality: 144 per 1000 children. Access to sanitation: 29%. Access to water: 27% of urban pop. HIV: 5.98% of adults. Female Youth Illiteracy: 61%, Male Youth Illiteracy: 27%. Togo has an "Association Togolaise Contre l'Epilepsie" (ILAE chapter). There are 5 Neurologists, 1 Neurosurgeon and 4 Psychiatrists. There are 4 EEG machines, 2 CT scanners and no MRI.

### UGANDA

Area: 236 040 km<sup>2</sup>. Population: 23.3 million (mn). Projected Population by 2030: 41 mn. Rural Population: 86% of total. Low-income country. Public Health Exp: 4.1% of GDP. Life Expectancy at Birth: 44 yrs. Under-5 mortality: 170 per 1000 children. Access to sanitation: 75% of urban pop. Access to water: 50%. HIV: 8.30% of adults. Female Youth Illiteracy: 46%, Male 24%. There are 6 Neurologists, 2 Neurosurgeons, 9 Psychiatrists, 4 EEG machines and 2 CT-Scanners. There is a drugs bank, and an epilepsy advisory board to advise the government. There is an IBE chapter but no ILAE chapter.

## ZAMBIA

Area: 752 610 km<sup>2</sup>. Population: 10.4 million (mn).  
Projected Population by 2030: 16 mn.  
Rural Population: 61% of total. Low-income country.  
Public Health Exp: 5.9% of GDP. Life Expectancy at Birth: 44 yrs. Under-5 mortality: 192 per 1000 children. Access to sanitation: 78% of urban pop. Access to water: 64%. HIV: 19.95% of adults. Female Youth Illiteracy: 31%, Male Youth Illiteracy: 16%. There are 2 Neurologists and 10 Psychiatrists; 1 EEG machine, 3 CT-Scanners and 1 MRI. There is an IBE chapter but no ILAE chapter.

## ZIMBABWE

Area: 390 580 km<sup>2</sup>. Population: 12.6 mn. Projected Population by 2030: 16 million (mn).  
Rural Population: 66% of total. Low-income country.  
Public Health Exp: 6.2% of GDP. Life Expectancy at Birth: 41 yrs. Under-5 mortality: 125 per 1000 children. Access to sanitation: 68% of urban pop. Access to water: 85%. HIV: 25.06% of adults. Female Youth Illiteracy: 17%, Male: 8%. There are: 1 Neurologist, 5 Neurosurgeons, 10 Psychiatrists, 5 EEG machines, 9 CT-Scanners and 3 MRI. The Epilepsy Support Foundation of Zimbabwe (IBE) and the ILAE chapter are providing education and organize support groups. Zimbabwe is a GCAE Demonstration Project site.



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*Anyone interested in following the progress of the Campaign will be able to do so from the regular updates on the relevant web sites:*

[www.who.int/mental\\_health/management/](http://www.who.int/mental_health/management/)  
[www.globalcampaign-epilepsy.org](http://www.globalcampaign-epilepsy.org) (joint IBE/ILAE Campaign site)  
[www.ibe-epilepsy.org](http://www.ibe-epilepsy.org)  
[www.ilae-epilepsy.org](http://www.ilae-epilepsy.org)  
[www.whoafr.org/mentalhealth/index.html](http://www.whoafr.org/mentalhealth/index.html)

