Epilepsy in the Western Pacific Region

A call to action

Global Campaign Against Epilepsy

World Health Organization
Regional Office for the
Western Pacific

IBE
International
Bureau for Epilepsy

International League
Against Epilepsy

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Contents

The burden of epilepsy in the Western Pacific Region of WHO is as extensive and serious as in any other region of the world. Epidemiological surveys in several countries have shown high incidence and prevalence of epilepsy, with high associated disability and high rates of serious complications, including physical injury and premature mortality. Studies have also demonstrated that most people with epilepsy do not receive appropriate treatment. The "treatment gap" in less developed countries is an estimated 70% to 95%. Safe, effective and inexpensive medication exists that can control seizures in most people with epilepsy but a range of cultural, economic and other factors can prevent them from receiving the treatment they need.

In 2001, three initiatives came together, marking an unprecedented opportunity to remedy this situation in the Western Pacific Region. These were: (1) continued implementation of the Global Campaign Against Epilepsy (GCAE), launched in 1997; (2) the adoption of epilepsy as a priority in the Regional Strategy for Mental Health which was endorsed by the 52nd Regional Committee of the Western Pacific Region in Brunei Darussalam in September 2001; and (3) the inclusion of epilepsy as a priority condition in the World Health Report 2001.

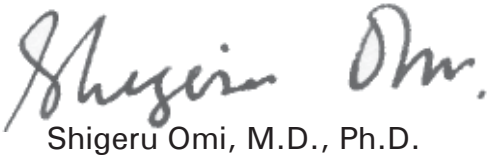
The GCAE, entitled "*Out of the shadows*", is a joint project of the International League Against Epilepsy (ILAE), the International Bureau for Epilepsy (IBE), and the World Health Organization (WHO). The aims of the GCAE are to reduce the worldwide burden caused by epilepsy by reducing the stigma and ignorance surrounding the disorder and improving treatment, services and prevention.

The first phase of the GCAE emphasized advocacy and raising awareness. Conferences on the public health aspects of epilepsy were organized in various parts of the world, and several Declarations on Epilepsy were adopted. An Asian and Oceanian Declaration was adopted at a meeting of the Asian and Oceanian Epilepsy Organization (AOEO) in New Delhi, India, in November 2000. Following the adoption of that Declaration on Epilepsy (Appendix 4), and the launch of the Second Phase of the Global Campaign in February 2001 in Geneva, many activities have taken place in the Western Pacific Region.

During the second phase, the GCAE is promoting the initiation and implementation of demonstration projects to assess needs for care, develop services and evaluate their

introduction. The first and largest GCAE demonstration project is located in the Western Pacific Region, in central China, covering five provinces and 2.5 million people. The project aims to raise awareness of, and diminish, the treatment gap for epilepsy and to reduce the stigma of epilepsy. Health workers are being trained and low-cost and effective treatments promoted. Initial results of the epidemiological investigations suggest that the prevalence of epilepsy is higher than first thought (7 out of 1000 population) and that the treatment gap is at least 70%. This project in China was designed to provide an important example for service development and evaluation within the Region.

It is evident that the collaboration between ILAE, IBE and WHO has given the GCAE 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 nongovernmental organizations are clearly the way forward to bring epilepsy "out of the shadows" as the situation in the Western Pacific Region proves.



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Preface

Worldwide epilepsy is the most common serious brain disorder, it affects 50 000 000 people directly. Epilepsy is one of the oldest known disorders. Epilepsy is responsible for an enormous amount of suffering. Epilepsy is a global problem affecting all ages, races, social classes and countries and it occurs in both men and women. People with epilepsy are viewed with fear, suspicion and misunderstanding People with epilepsy are subject to horrendous stigma. Epilepsy imposes enormous physical, psychological, social and economic burdens on individuals, families and countries, especially due to misunderstanding, fear and stigma. Many people with epilepsy suffer in silence, afraid to be found out.

The above-mentioned problems are universal but are greatest in the developing world where 85% of the 50 000 000 people with epilepsy live.

At the same time epilepsy provides the clearest example of a neurological disorder for which effective and cost-efficient treatments are 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. In developing countries, however, up to 90% of the people who have this condition and, sometimes even more, remain excluded from receiving care and remain in the shadow of this treatment gap.

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

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

The Campaign strategy involves two parallel tracks:

- raising general awareness and under-standing of epilepsy; and
- supporting national departments of health in identifying needs and in promoting education, training, treatment, services, research and prevention nationwide.

The tactics are:

1. to generate regional declarations on epilepsy by:
    - producing regional reports and other relevant materials;
    - incorporating epilepsy care in national health plans;
    - facilitating the establishment of national organizations of professionals and of laypersons who are dedicated to promote the well being of people with epilepsy; and
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.

This document is part of a series of similar documents that have been or will be published in all six WHO Regions and will serve as a tool for dialogue with governments, health care providers and other interested parties. It contains information on activities performed under the aegis of the Campaign in the Western Pacific Region. The results of a questionnaire on country resources for epilepsy are also included which provide a profile of the epilepsy services and programmes available in the public sector. The information available in this series of epilepsy-related documents will provide a framework for improving services at the individual country level. Programmes to prevent and control epilepsy and reduce the social stigma will be strengthened through the combined efforts of the Global Campaign Against Epilepsy and those at country level.

The Regional Report is a publication jointly developed by the WHO Regional Office for the Western Pacific, WHO Headquarters and by the Secretariat of the ILAE/IBE/WHO Global Campaign Against Epilepsy.

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Abbreviations

AED: Antiepileptic drug

CT: Computerised tomography

DALY: Disability Adjusted Life Year

EEG: Electroencephalogram

GCAE: ILAE/IBE/WHO Global Campaign Against Epilepsy

IBE: International Bureau for Epilepsy

ILAE: International League Against Epilepsy

MEG: Magnetic mapping

MRI: Magnetic resonance image

PET: Positron emission tomography

SMR: Standardised mortality rate

SPECT: Single photon emission

WHO: World Health Organization

WHO/HQ: World Health Organization/ Headquarters

WPRO: Western Pacific Regional Office

Nestor

16 years, Philippines

I always looked forward to spending my summer vacation in the rural areas because of the fresh scent of air, the flying of kites, fishing expeditions and other activities. Until one day, when my cousin had an epilepsy of “patol”. The seizure lasted only for a few seconds but his agony seemed a lifetime. I can still recall how he was tied to the bedpost and was given amulets to protect him from evil forces. Late at night I heard him crying. I pitied him so much that I went to his room and untied him and told jokes just to ease his pain of loneliness and helplessness. Instead of seeking medical attention they are hidden from the public to prevent humiliation, leaving the victims with inappropriate care leading to deterioration of health. Let’s chase away the myth that mental and brain disorders are caused by evil spirits or forces.

1. Introduction

Epilepsy is the most common serious neurological disorder and one of the world's most prevalent non-communicable diseases. As the understanding of its physical and social burden has increased, it has moved higher up on the world health agenda. A conservative estimate is that there are 50 million people worldwide with epilepsy. Of these, over 80% are thought to be in developing countries. The World Bank report "Investing in Health" (1993) states that in 1990 epilepsy accounted for nearly 1% of the world's disease burden.

Epilepsy largely results from preventable causes and is treatable with relatively safe and inexpensive drugs. However, in developing countries, an immense treatment gap has been demonstrated: around 70% to 90% of people with epilepsy do not receive appropriate treatment, let alone comprehensive care. In both developed and less-developed countries, people with epilepsy continue to be stigmatised and to have a lower quality of life than people with other chronic illnesses.

However, even though treatment exists, bridging the treatment gap and reducing the burden of epilepsy is not straightforward and faces many constraints. Among the many factors, cultural attitudes, a lack of policy prioritisation, poor health system infrastructure, and inadequate supply of anti-epileptic drugs (AEDs) stand out as obstacles to appropriate treatment.

To bring epilepsy to the forefront as a health priority, a Global Campaign Against Epilepsy (GCAE) has been organised by the International League Against Epilepsy (ILAE), the International Bureau for Epilepsy (IBE), and the World Health Organization (WHO). The aims of the GCAE are to improve the acceptability, treatment, services and prevention of epilepsy worldwide.

There have been successful attempts to provide treatment that have shown, first, the importance of community-based approaches and, second, the need for interventions to be sustained over the long term. Approaches being adopted by the demonstration projects of the GCAE will provide additional information about how to ensure that epilepsy programmes are well targeted and sustainable. Much remains to be done, but the GCAE provides a historic opportunity to enhance the lives of people with epilepsy in both developing and developed countries.

Necessary data are lacking, which is a key aspect of the overall problem and will be considered further in this report. However the data that do exist suggest that the public health burden of epilepsy in the Western Pacific Region is similar to that in the

rest of the world. For example, recent work in China showed that there are between six and nine million people with active epilepsy, over 60% of whom do not receive appropriate treatment [1].

Similar to other WHO regions, the Western Pacific Region, which is composed of 37 countries and territories, encompasses an extraordinary diversity of cultures, socioeconomic structures, and health service arrangements. Even within the developed countries of the Western Pacific Region, there are the serious problems of stigma, social disadvantage (both contributing to the burden of epilepsy), lack of necessary epidemiological data and lack of access to appropriate treatment.

Epilepsy is a disorder considered in the 2001 WHO Regional Strategy for Mental Health. Member States in the Region were urged to develop national policies and plans to improve awareness and understanding, to reduce the burden of the disorder and to develop preventive strategies. Starting with some general considerations about epilepsy and moving to the Western Pacific Region specifically, this report summarises the current situation concerning epilepsy, its public health impact, past and present activities in community-based control, and directions for further action.

2. Epilepsy in the Western Pacific Region: The current situation

2.1 Definition of epilepsy

The word "epilepsy" derives from the Greek verb "*epilambanein*", meaning "*to be seized, to be overwhelmed by surprise*" and captures well the sudden, usually unpredictable and intrusive nature of most seizures. Neurologists define epilepsy as: "*a condition in which individuals experience paroxysmal changes in behaviour caused by abnormalities in the electrical activity of the brain*" [2]. In other words, epilepsy is the name given to a group of functional disorders of the brain that are characterized by repetitive seizures. Seizures involve abnormal, excessive electric discharges of groups or assemblies of nerve cells (neurones) in the brain.

Epileptic seizures are non-specific responses of the brain to a wide variety of insults. Therefore, epilepsies may have many different causes. By convention, for epidemiological purposes, a diagnosis of epilepsy requires the patient to have had a minimum of two "unprovoked" seizures during the previous year. The term "provoked" seizure means a seizure which is the immediate consequence of an acute cerebral disorder, e.g. encephalitis or brain trauma. ILAE has classified seizure types and syndromes, i.e. the epilepsies, in order to facilitate communication and research.

Before outlining the scope of the problem in the Western Pacific Region, it is useful to make preliminary comments about the definition of epilepsy and about epidemiological approaches to epilepsy. The main concepts to consider are those of *prevalence* and *incidence; mortality* and *standardized mortality ratio; risk factors* and *causes* and, related to these, *idiopathic cryptogenic* and *secondary* epilepsy[1]*; disability and disability adjusted life year (DALY); quality of life; and co-morbidity.* In this report, definitions are consistent with other recent publications associated with the GCAE. In keeping with thinking in recent decades, epidemiology in this report is conceived broadly to encompass also the social and economic aspects of states of health and ill-health.

Epilepsy exemplifies the distinction that has been made between *impairment, activity limitations and participation restrictions*[2] [3]. Looking more closely at the elements of disability, *impairment* refers to problems in body function or structure, to lesions and dysfunctions, such as,

[1] The terminology in this area presents some problems and has been the subject of considerable debate and calls for revision. This is discussed in detail in reference 2.

[2] This superseded a previous distinction between *impairment, disability* and *handicap.*

in the case of epilepsy, hippocampal sclerosis in most cases or paroxysmal discharges apparent on the electroencephalogram (EEG). The *activity limitations* in functioning due to epilepsy are considerable, but so too are the *participation restrictions* [4].

The *activity limitations,* which may stem from the underlying brain disorder from the seizures themselves, or sometimes from treatment, include both episodic and continuing dysfunction in thinking, behaviour and movement, which may secondarily affect performance in work, leisure and relationships and result in physical injury.

The *participation restrictions* include discrimination in education, employment, social relationships and the law. At certain times and in some countries, this has included legislation prohibiting marriage and having children. In many cultures, lack of understanding of epilepsy, of mental illness, and of the relationship between the two has undoubtedly resulted in an intensification of the stigma accorded to both.

In brief, epilepsy, as one of the major brain disorders and a common noncommunicable disease, has great public health importance especially in developing countries. In addition to its prevalence, the importance of the epilepsies stems from two aspects of the problem: on the one hand they are disorders which are treatable, preventable and – in some patients – curable[3]; on the other hand, there is a lack of social awareness and understanding of the disorder; health services are inadequate; there may be severe physical, mental and socio-psychological impact on individuals; the emotional and practical effects on families of people with epilepsy are profound; and the economic and policy challenges for societies are very substantial. Although there are elements in common, the scale and nature of the problem are very different in developed and developing countries [5], as is the case with most health disorders [6].

2.2 Epidemiology and public health impact of epilepsy

2.2.1 Epidemiology

"Epidemiology is the study of the distribution and determinants of disease in human populations..." [7]. Recently, psychosocial and economic indicators, such as quality of life and standards of care, have been incorporated into epidemiological research, as their relationship to morbidity became evident. Epilepsy knows no geographical, racial or social boundaries and occurs in both men and women. It can begin at any age, but in developed countries onset occurs more often at the extremes of life, i.e. during infancy, childhood, and adolescence and in old age; in developing countries there is a preponderance of childhood onset.

[3] The existence of cure or permanent remission from epilepsy is an important point, not widely known by the public. That epilepsy can be cured or controlled argues against the fatalism and pessimism which surrounds this illness. Examples include benign childhood epilepsy with centro-temporal spikes, which often remit, and cure of mesial temporal epilepsy by temporal lobe surgery.

There are several key difficulties in conducting epidemiological research on epilepsy and in interpreting the epidemiological literature [7, 8]. These difficulties include:

- variations in the definitions and classification of seizures and of epilepsy;
- poor case ascertainment due to ignorance or concealment by patients or their families; or due to the fact that some patients are not aware of having seizures (e.g. subtle seizures, nocturnal seizures);
- diagnostic imprecision, even when potential patients are identified; and
- differences between studies in the age distribution of study populations, or in the place or mode of recruitment of subjects.

These and other factors all limit the precision and validity of data and comparability among studies. Despite these difficulties, sufficient data are available from numerous studies to give a useful profile of the broad epidemiological characteristics of epilepsy [9, 10]. In addition, a simplified classification scheme has been proposed that may be of greater utility in epidemiological work [11].

(a) Prevalence

Table 1 shows prevalence rates from different countries. The lowest prevalence was from Singapore (1993), at 3.8 per 1000 population, and the highest from Panama (1988), at 57 per 1000 population. There have been few prevalence surveys in the Western Pacific Region, but from the figures shown for China and Japan, the prevalence of epilepsy in the Region would be similar to the average

Table 1. Prevalence and incidence of epilepsy
(Adapted from (10) and (12-15))

Country/Area	Year	Prevalence (per 1000 population)	Incidence (per 100 000 population per year)
United States of America	1996	6.8	44
United Kingdom	1995	4.3	48
Japan	2001	8.9	-
China	1985	4.4	35
China	2001	4.6	29
Africa	2002	5 to 58	73 to 140
Ecuador	1992	6.7 to 8	122 to 190
Panama	1988	57	-
Pakistan	1997	10	-
Japan[a]	1975	8.2	145
Singapore	1993	3.8	-

[a] This study from Japan included only children less than 10 years old.

global figure. The reasons for the wide variation of reported prevalence between different countries are complex and warrant further study.

(b) Incidence

Most epidemiological studies of epilepsy find an incidence rate of 20 to 70 per 100 000 population per year (with a range of 17 to 190 per 100 000 population as shown in Table 1). The rates are higher in developing countries, where rates are roughly double those in developed countries. The incidence is higher in men than in women and varies considerably with age: it is high during childhood, decreases among young people and rises again among the elderly.

(c) Mortality rates

Premature mortality due to epilepsy is a serious problem that is underestimated worldwide. An indication of the scale of the problem is provided in Table 2. Although this table provides estimates of total numbers (rather than rates) it highlights the differences in the global burden of epilepsy mortality.

In recent years, the standardised mortality rate (SMR) has been used in the epidemiological literature to analyse deaths associated with epilepsy. These analyses show that the SMR for epilepsy patients is more than twice that for the general population.

Causes of mortality include [16]: (1) underlying brain diseases, such as tumour or infection; (2) seizure-related deaths (status epilepticus; drowning, burns or other trauma; severe aspiration or airways obstruction by food etc; deaths caused by habitual seizures when coexisting with cardiorespiratory disease); (3) suicide; (4) death as a consequence of medical or surgical treatment of epilepsy; and (5) SUDEP (Sudden Unexplained Death in Epilepsy), whose causes remain poorly understood [16].

Table 2. Global estimated total deaths from epilepsy in 1990 in developed and developing regions [7]

Region	Population (million)	Epilepsy mortality (total number in thousands)
Established Market Economies	797.8	7.4
Formerly Socialist Economies of Europe	346.2	5.2
India	849.5	31.2
China	1133.7	16.0
Other Asia and Islands	682.5	19.6
Sub-Saharan Africa	510.3	15.1
Latin America and Caribbean	444.3	8.8
Middle Eastern Crescent	503.1	11.7
World	5267.4	115.2

Risk factors. Table 3 shows the results of two case-control studies which were conducted in six cities in 1983 and in rural areas of 22 provinces in 1985 in China [23]. The risk factor findings broadly match those of a number of studies in other countries [7, 8].

Many epidemiological studies implicate genetic factors, perinatal factors and history of febrile seizures as risk factors for various major kinds of epilepsy, although there is not complete agreement about these factors.

In most studies, populations with poor perinatal health care, high incidence of premature births and head trauma during delivery, and high infant mortality are at high risk for epilepsy. The major perinatal factors include short gestation, low birth weight, prolonged labour, neonatal asphyxia, and assisted delivery.

When epilepsy appears to be caused by a clinically identifiable brain disease, it is categorized as "symptomatic epilepsy". These causes include: head injury; intracranial infection, e.g. neurocysticercosis, malaria; cerebrovascular disease; brain tumour; drugs and alcohol; carbon monoxide poisoning; and effects of ionizing radiation

Febrile illness of any kind can trigger seizures in young children. About 3% of children who have *febrile convulsions* go on to develop epilepsy later in life.

Some investigations suggest that rural populations with poor health services and disadvantaged urban populations should be included in the high risk group for epilepsy. The relevant factors among these populations are poverty and *low socioeconomic status*, which are themselves associated with high rates of epilepsy — as they are with so many other disorders. One of the clearest indications of the relative contributions of various causes of epilepsy came from the retrospective study in six cities of China [17]. The three most common causes of epilepsy, head injury, intracranial infection and cerebrovascular disease, which together accounted for 88.5% of cases, are all in principle preventable conditions.

Table 3. Risk factors for idiopathic epilepsy
(Case-control studies in six cities and rural areas of 22 provinces of China)

	6 cities		22 rural areas	
Expected risk factor	RR[a]	*P*<	RR	*P*<
Parents' intermarriage	-	(>0.05)	9	0.001
Epileptics in family	2.5	0.01	15.4	0.001
Previous febrile seizures	7.5	0.01	32.2	0.001
Premature or difficult labour	3.2	0.025	13	0.001
Born when mother >30 yrs of age	1.5	0.05	1.4	0.025

[a] RR (Relative Risk) = B/C; B = case (+), control (-); C = case (-), control (+).

Table 4. Putative causes of symptomatic epilepsy cases in six Chinese cities

Putative cause	No. of cases	%
Head injury	29	47.5
Intracranial infection	15	24.6
Cerebrovascular disease	10	16.4
Intracranial tumour	2	3.3
Other	5	8.2
Total	61	100

Table 4 shows the results of the retrospective study in six cities of China.

(d) Prognosis

The incidence rates in epidemiological surveys are typically in the range of 20 to 70 per 100 000 population, suggesting expected lifetime prevalence of between 2% and 5%. However, prevalence surveys consistently produce estimates around 0.5% to 1%. This alone suggests that for a majority of patients there is a very good prognosis if diagnosed and treated appropriately.

In general, AEDs can control seizures in up to 70% of patients and with regular treatment a similar number can experience lasting remission. Still, 20% to 30% of patients continue to have seizures despite treatment with a range of AEDs. Some patients can be helped with surgical treatment, which has been shown to be safe and effective [18] but which is currently is underutilised for a range of reasons [5, 19].

The most vulnerable groups are women and children. Women with epilepsy have concerns regarding the effects of their condition and the use of AEDs on their unborn children. These concerns fall into four areas: increased seizure frequency during pregnancy, risk of birth defects, risks associated with breast-feeding, and psychomotor retardation in offspring. Studies have shown that many of these risks can be minimised with appropriate management and counselling. Children with uncomplicated epilepsy, idiopathic etiology and eventual remission without medication ("natural remission") do less well than their matched controls in basic and vocational education and in later reproductive activity.

2.2.2 Impact on quality of life of individuals with epilepsy

Fear, misunderstanding and the resulting social stigma and discrimination surrounding epilepsy often force people with this disorder "into the shadows". The social effect may vary from country to country and culture to culture, but it is clear that throughout the world the social consequences of epilepsy are often more difficult to overcome than the seizures themselves [20].

In most countries, epilepsy stands out as one of the most stigmatised and misunderstood health disorders. The

stigmatisation is particularly pronounced in less-developed countries. Extraordinary prejudices and biases abound concerning people with epilepsy. For example, children with epilepsy find themselves confronted with social barriers that prevent them from academic achievement, in addition to the range of other limitations that the disorder itself has already placed on them. Significant problems are often experienced by people with epilepsy in the areas of personal relationships. In China, epilepsy is commonly viewed as a reason for prohibiting or annulling marriages. A survey of public awareness in 1992 revealed that 72% of parents objected to their children marrying someone with epilepsy.

In many countries, legislation affecting people with epilepsy reflects centuries of suspicion and misunderstanding. In some countries legislation suggests that people with epilepsy can be prevented from marrying or having children. In Japan, the law concerning driving a vehicle was very restrictive for people with epilepsy. Even persons with many years of remission were unable to obtain a driver's license (the law was amended in 2002, easing such restrictions).

Finally, unemployment and underemployment exist worldwide, but more so among people with epilepsy. The misunderstandings and stigma mentioned previously are usually to blame for this.

These problems may in turn undermine the treatment of epilepsy. Public and professional education to raise public and professional awareness are essential to rid the world of this stigma.

Data from Japan show that the majority of patients with childhood-onset epilepsy have a favourable long-term medical prognosis in terms of seizure remission and psychiatric complications. Nevertheless, these patients had a higher mortality rate, lower levels of educational attainment, lower employment and marriage rates and lower rates of holding a driver's licence compared with the general population.

2.2.3 Economic costs of epilepsy

Epilepsy has always imposed an economic burden both on the affected individuals and on society. For example, the disease commonly affects young people in the most productive years of their lives, often leading to avoidable unemployment [21, 22]. The costs of epilepsy go beyond the impact on employment; they include the costs of care, for support services, and the opportunity costs associated with the disorder.

The study of the economic impact of epilepsy started only in the 1990s. Since then, the number of publications on the topic has risen substantially. A study in Australia was conducted

in 1992 to quantify the economic cost of epilepsy (Australia remains the only country in the Western Pacific Region to have conducted such research). The study underscored the significant costs to individuals and the community at large, stemming from epilepsy. The estimated major direct costs of epilepsy in Australia for health care was more than AU$ 238 million per annum. The indirect costs of epilepsy in Australia may be approximated as follows:

- AU$ 6.6 million for time lost from work resulting from attendance for medical care
- AU$ 75.7 million for unemployment benefits
- AU$ 37.2 million for disability support pensions
- AU$ 87.7 million for other support allowances
- AU$ 2.6 million to provide for institutional infrastructure of epilepsy-related organisations

Economic factors are playing an increasing role in decision-making processes and in guiding decisions on the allocation of health care services. Health care providers are required to target limited resources and, increasingly, to justify their decisions.

From an economic point of view, it is an urgent public health challenge for the 21st century to make effective epilepsy care available to all who need it, regardless of national and economic boundaries. In 1990, WHO identified that the average cost of the AED phenobarbitone (which alone could be used to control seizures in a substantial proportion of people with epilepsy and which is on the WHO list of essential drugs) could be as low as US$ 5 per person per annum.

2.2.4. Summary

In summary, on the basis of a literature review and extrapolation from the literature from the rest of the world, including many studies in less-developed countries [23, 24, 25], one can conclude that the following problems exist in the Western Pacific Region:

- There are no or insufficient epidemiological data, resulting in unreliable estimates of the burden of epilepsy in most countries of the Western Pacific Region.
- Little attention is given to public education on epilepsy, so that misunderstanding and social stigma persists largely unchallenged.
- Neurologists and health services for epilepsy are lacking or not properly distributed.
- Most people with epilepsy are not diagnosed and treated appropriately [26].
- Proper legislation on and coordination of epilepsy among government sectors (such as public health, education, labour, etc.) are needed.
- Superstition and unscientific and popular therapies need to be combated or tested using scientific methods. Fraudulent therapies need to be controlled by law.
- Further research on epilepsy, especially on the public health aspects, is needed.
- Professional and lay organisations, epilepsy foundations, and networks of epilepsy centres need to be developed.

3. The Global Campaign Against Epilepsy (GCAE) in the Western Pacific Region

The GCAE, initiated in 1997 by ILAE, IBE, and WHO, is aptly entitled "*Out of the Shadows*" [27]. Such a campaign is greatly needed. The burden of epilepsy is underestimated and the means available to reduce this burden are underutilized. Moreover, the problem is too complex to be solved by individual organisations. The Campaign will assist governments worldwide to improve diagnosis, treatment, prevention and social acceptability of epilepsy.

3.1 The Campaign strategy

Working along two parallel tracks, the Campaign will:

- raise general awareness and understanding of epilepsy; and
- support departments of health to identify needs and promote education, training, treatment, services, research and prevention in the respective countries.

3.2 Objectives of the GCAE

The objectives of the GCAE are:

(1) to increase public and professional awareness of epilepsy as a universal treatable brain disorder;

(2) to raise epilepsy to a new plane of acceptability in the public domain;

(3) to promote public and professional education about epilepsy;

(4) to identify the needs of people with epilepsy; and

(5) to encourage governments to address the needs of people with epilepsy.

3.3 The Campaign tactics

The objectives of the Campaign are to be achieved by:

- generating Regional Declarations on Epilepsy, producing information on epilepsy for policy-makers, incorporating epilepsy care into national health plans, and facilitating the establishment of national organisations of professionals and lay persons dedicated to promoting the well-being of people with epilepsy; and
- organising demonstration projects that illustrate good practice in the provision of epilepsy care. External funds will be used to initiate the projects, but will not be used to provide services or medication as it will be shown that epilepsy care is locally sustainable.

3.4 GCAE in the Western Pacific Region

The GCAE has supported a number of important initiatives in the Western Pacific Region, including:

(1) the launching of a demonstration project titled "Epilepsy Management at a Primary Health Level" in China;

(2) holding a regional consultation on epilepsy, which took place in Manila, the Philippines in November 2001. This meeting brought together professionals, representatives of key nongovernmental organisations, WHO Country Representatives and Country Liaison Officers from selected countries, and leaders of the GCAE to review epilepsy prevention and control in the Region and to propose further plans for action; and

(3) performing a survey on country resources for epilepsy in all 37 countries and territories in the Region.

3.5 Demonstration project in China

The demonstration project in China ("Epilepsy Management at a Primary Health Level") includes an epidemiological survey, an intervention study and an educational programme in five provinces (Heilongjiang, Ningxia, Henan, Shanxi and Jiangsu). First, an epidemiological survey was performed in the demonstration areas. During the first phase, the lifetime prevalence was found to be 7 per 1000 population and the active epilepsy[4] prevalence was 4.6 per 1000 population. Sixty-three percent of the patients with active epilepsy did not receive any treatment during the week prior to the survey.

The second phase (intervention study) began with a compulsory training for primary health care physicians. A diagnostic questionnaire was used to identify patients with convulsive epilepsy. Local neurologists (supervising doctors) were responsible for the inclusion of patients into the intervention study. During the intervention phase compliance was also assessed. Ninety-five percent of the patients complied during the treatment period possibly because they were followed conscientiously by their physicians.

The project is expected to be completed in 2005.

3.6 Regional consultation on epilepsy

A meeting of the countries of the Western Pacific Region was organised by the WHO Regional Office in collaboration with the GCAE Secretariat. The main objectives were:

- to review the present state of epilepsy in the Region;
- to discuss a draft Regional Report on Epilepsy;

[4] Active epilepsy: two or more unprovoked seizures in the previous 12 months.

- to review the implementation of the GCAE in the Region, including the progress of the demonstration project in China; and
- to develop a framework of action for countries in the Region.

At the end of the meeting, action was recommended in seven areas:

(1) Setting-up (or further development) of lay and professional epilepsy organisations.

(2) The design and implementation of community-based treatment and prevention services.

(3) The promotion of public education regarding epilepsy using a range of avenues and methods: in schools, through written and mass media, and/or utilising "epilepsy days".

(4) The design and implementation of relevant epidemiological research on prevalence and on the treatment gap, as well as on lay epilepsy knowledge, attitudes and practices.

(5) The identification of potential areas of inter-country cooperation and information exchange.

(6) The reform of legislation which discriminates against persons with epilepsy.

(7) The identification of methods and avenues for fund-raising or "resource mobilisation".

3.7 Questionnaire on country resources for epilepsy

"A Questionnaire on Country Resources for Epilepsy" designed by ILAE, IBE and WHO was used for a survey in the WHO Western Pacific Region. The results of the survey are included in Appendix 3, and the survey instrument is attached as Appendix 5.

The questionnaire comprised nine sections with an additional section for comments. The nine areas of enquiry were:

(1) professional organisations of epilepsy specialists;

(2) other lay and professional epilepsy organisations;

(3) causes of epilepsy in each country;

(4) epilepsy care and services;

(5) human resources;

(6) training in epileptology;

(7) financing for epilepsy services;

(8) information and data collection systems; and

(9) drugs and other treatments.

Figure 1. Member states and associate members in the WHO Western Pacific Region

There are 37 member states and associate members in the WHO Western Pacific Region, as shown in Figure 1, all of whom were requested to complete the questionnaire.

To date 25 countries/territories have completed the questionnaire: Australia, Cambodia, China, Cook Islands, Fiji, French Polynesia, Japan, the Republic of Korea, the Lao People's Democratic Republic, Malaysia, Marshall Islands, the Federated States of Micronesia, Mongolia, New Zealand, Niue, Palau, Papua New Guinea, the Philippines, Samoa, Singapore, Solomon Islands, Tokelau, Tonga, Vanuatu and Viet Nam. The respondents include responsible national health authorities, professionals responsible for national epilepsy organisations, and, in some small countries, neurologists or nurses treating people with epilepsy.

3.7.1 Results

(a) Organisations related to epilepsy existing in the Region

(1) Professional societies of epilepsy specialists: Of the 25 countries, 28% responded that professional societies do exist: Australia, China, Japan, the Republic of Korea, Malaysia, the Philippines and Singapore. A total number of 2781 specialists were registered members. Of these specialists, 55.7% were from Japan and 16.4% from the Republic of Korea. The main activities of these societies were: organising professional meetings and conferences on epilepsy; publishing guidelines and recommendations on epilepsy; advocacy for epilepsy-

related issues; and advising the government on epilepsy and epilepsy-related issues.

(2) Other organisations dealing with epilepsy: 48% of countries reported to have such organizations, concerned with neurology, psychiatry, paediatrics or social welfare. The main activities of those organisations were: awareness raising and advocacy, treatment, education, rehabilitation and prevention.

(b) Epilepsy care and services

Major problems concerning care and services. Five major problems concerning epilepsy care and services encountered by the health professionals involved in epilepsy care, are listed below:

(1) difficulties related to treatment including: difficulties in selecting methods of treatment; availability, selection and dosage of AEDs; patient compliance; pre-surgical evaluation and method of surgery, etc.;

(2) difficulties related to epilepsy care infrastructure and facilities, including the treatment gap in rural area; lack of neurologists, paramedical personnel; and continuing education, referral system, research, nursing support, etc.;

(3) social ignorance and stigmatization of the patients;

(4) financial difficulties in epilepsy care including shortage of government funding, health insurance and high cost of new AEDs; and

(5) difficulties in diagnosis including access to sophisticated diagnostic facilities and rehabilitation.

The respondents identified the following five major problems encountered by people with epilepsy:

(1) personal difficulties in education and employment;

(2) accessibility of epilepsy care service and AEDs;

(3) financial difficulties: health insurance, high cost of AEDs;

(4) discrimination and stigma, marriage difficulties; and

(5) others: safety, rehabilitation, fear, AED side-effects, etc.

Major tasks for care-providers. The respondents identified the following main tasks for primary care workers involved in epilepsy care:

(1) appropriate treatment including initiation and determination of AEDs;

(2) maintenance of and screening for side-effects and toxicity of drugs, management of seizures;.

(3) community education, counselling and rehabilitation;

(4) "follow-up".

Availability of specialists and services. Among the 25 countries, only nine countries — Australia, China, Japan, Malaysia, New Zealand, the Philippines, the Republic of Korea, Singapore, and Viet Nam — have epilepsy specialists. In addition, in Solomon Islands there are six psychiatric nurses who are recognized as epilepsy specialists.

The most important services they provide to people with epilepsy concern diagnosis, treatment, following-up, consultation, community education and rehabilitation. With respect to treatment, the specialists' job is related to treating intractable cases, selecting and changing AEDs, pre-surgical evaluation and surgical treatment. Available diagnostic facilities are listed in Table 5.

Available sub-specialised epilepsy services are shown in Table 6.

Private sector. The proportion of private ownership of epilepsy services in some countries in the Region is as follows:

The Republic of Korea and the Philippines	80% to 90%
Japan, Vanuatu and Singapore	5%
China and Palau	10%
The Lao People's Democratic Republic, Malaysia, Papua New Guinea and Viet Nam	0%

Table 5. Availability of diagnostic procedure

Diagnostic procedure	Number of countries	Percent of the 25 countries
Computerised axial tomography (CT)	14	56
Electroencephalography (EEG)	13	52
Magnetic resonance image (MRI)	9	36
Single photon emission (SPECT)	3	12
Positron emission tomography (PET)	2	8
Functional MRI	1	4
Magnetic mapping (MEG)	1	4
Angiography DSA	1	4

Table 6. Available sub-specialized epilepsy services

Category of service	Number of countries	Percent of the 25 countries
Psychiatric counselling	16	64
Therapeutic drug monitoring	11	44
Special education	10	40
Neuropsychological services	9	36
Long-term video/EEG monitoring	7	28
Epilepsy surgery	7	28
Social rehabilitation	5	20
Sheltered work	3	12

Table 7. Professionals involved for 50% + time in epilepsy care

Professional	CHN	KOR	PHL	SIN	MAA	VTN	LAO	MOG	Other countries
Specialist neurologists	5000	90	50	5	4	200	1	2	SAM 1
Neuro-paediatricians	2000	50	25	5	6	20		1	
Psychiatrists	5000	5	10			250	2	3	PAL 1
Neurosurgeons	100	10	5		1	30			
Neurological nurses	300	10		1					JPN 200 SOL 22
Psychologists			5		5	10			FSM 1 PAL 1
Social workers				1		10			NIU 2 PAL 2
Education specialists						20	6		

Notes: CHN = China, KOR = the Republic of Korea, PHL = the Philippines, SIN = Singapore, MAA = Malaysia, VTN = Viet Nam, LAO = the Lao People's Democratic Republic, MOG = Mongolia, JPN = Japan, SOL = Solomon Islands, FSM = the Federated States of Micronesia, NIU = Niue, SMA = Samoa, PAL = Palau.

Additional human resources. In terms of human resources in addition to the epilepsy specialists, the survey looked at the number of professionals in the country who are involved for 50% or more of their working hours in epilepsy care. The results of this survey question are included in Table 7.

Training in epileptology. Postgraduate specialist training is available in four of the 25 countries, i.e. Australia, China, the Republic of Korea and Japan. The duration of such training is six months in China, 12 months in Australia and the Republic of Korea and 72 months in Japan. The average number of graduates from the training programme per year in China, the Republic of Korea and Japan are 15, 10 and 20 respectively. The other 21 countries do not have this kind of training.

Financing and budget. There is only one country (Japan) that has a separate budget for epilepsy care in the Ministry of Health's budget. As for the proportion spent on epilepsy care of the overall health budget of the government, five countries replied as follows: Australia < 1%, China 0.1%, Japan 0.01%, Vanuatu 1% and Niue 2.5%. Financing of epilepsy services varies in different countries as shown in Table 8.

Eight of the 25 countries (32%) have disability benefits available to people with epilepsy. Such benefits include unemployment, disability pension, sickness benefit, travel subsidy and work cover (Australia), mental retardation (Japan), disability allowance (Mongolia, Niue and Palau), sickness benefit (Cook Islands), or parents pension (the Federated States of Micronesia). New Zealand did not mention any details.

Table 8. Financing of epilepsy services in the country*

Financing source	Number of countries	Percent of the 25 countries
Out-of-pocket payments	13	52
Tax-based funding	10	40
Private insurance	7	28
Social insurance	5	20
Private foundations	2	8

* In some countries epilepsy services can be financed in more than one way.

Information/data collection system. Nine of the 25 countries (36%) include epilepsy in the country's annual health reporting system and 12 countries (48%) have an epidemiological data collection system for epilepsy. Twelve countries also provide an estimate of the number of people with epilepsy (Table 9).

(c) Causes of epilepsy

The answers to the question concerning the five most common causes of epilepsy ranked in the following order:

- Head injury: traffic accidents
- Central nervous system infection
- Perinatal factors: difficult labour
- Cerebrovascular disease: stroke
- Unknown: genetic factors
- Intracranial tumour
- Parasitosis: cysticercosis
- Development lesions: cerebral malformation
- Benign febrile convulsion
- Others

Table 9. Estimated number of people with epilepsy

Country	Estimated number of people with epilepsy
China	8 000 000
Cook Islands	18
Japan	750 000
Malaysia	11 856
The Federated States of Micronesia	115
Mongolia	4065
Niue	9
Palau	6
Papua New Guinea	140
The Philippines	183 000
Solomon Islands	108
Vanuatu	89

Table 10. Anti-epileptic drugs licensed by the government

Name of AED	Over the counter AED	General practitioner needed AED	Specialist needed AED	AED included in the list of essential drugs
	No. of countries	No. of countries	No. of countries	No. of countries
Phenobarbital	7	13	13	8
Phenytoin	7	13	13	10
Carbamazepine	8	12	13	9
Valproic acid	5	12	13	7
Diazepam	4	6	6	4
Clonazepan	3	8	10	2
Nitrazepam		1	1	1
Lorazepam		2	2	
Primidone		4	4	2
Lamotrigine		3	4	
Zonisamide		1	1	1
Vigabatrin		1	2	
Topiramate		3	5	
Gabapentin		3	5	
Oxcarbazepin		1	2	
Ethosuximide		4	4	
Clobazam		3	3	1

(d) Anti-epileptic drugs and other treatments

The AEDs licensed by the governments in the 25 countries included in the survey are shown in Table 10.

The survey respondents. The respondents varied from country to country. In the countries with large populations, such as China, Japan, the Republic of Korea, they were professionals responsible for national epilepsy organisations whereas, for small Pacific island countries they consisted of health authorities or health workers responsible for epilepsy-related services. In any case, the respondents knew the situation of the programmes and services in the countries.

Reliability of data. The information provided may be considered reliable even though some "estimated" numbers should only serve as references. Questions included in the questionnaire were mostly qualitative, with some quantitative. Because of the large diversity of population size, socioeconomic situation, culture, etc. of the countries, the quantitative data, especially with respect to absolute numbers, has less significance. Since the population of the 25 countries who responded to the questionnaire (1 672 545 000) represents 99.5 % of the entire population of the 37 Member States and Associate Members in the Western Pacific Region of WHO (1 680 569 000), this report may be considered to be reliably representative of the whole Region.

Therefore, keeping in mind all factors mentioned above, this survey provides a rough picture of the epilepsy services and programmes in the Western Pacific Region.

3.7.2 Analysis of results

Epilepsy, as one of the major brain disorders and a common noncommunicable disease, has great public health importance especially in developing countries. The importance of epilepsy is two-fold. On the one hand, it is a disorder which is treatable, preventable and - in some patients - curable; on the other hand, there is a lack of social awareness as well as a lack of understanding of the disorder and existing health services are inadequate [28, 29].

The present survey shows that the scale, level, and efficiency of epilepsy services in the public sector are dependent upon the country's level of socioeconomic development and the importance that the government places on epilepsy control programmes. Thus, in industrialised countries such as Japan, the Republic of Korea and Singapore, there are high level epilepsy services including advanced facilities for diagnosis, treatment, social welfare and financial support. In some large developing countries in the Western Pacific Region such as China, Malaysia, the Philippines and Viet Nam, probably because the governments are aware of the importance of epilepsy and the burden of the disease, epilepsy services and programmes are also developed to some extent. However, in most of the Pacific Island countries, irrespective of the per capita income, epilepsy services are not adequate. In spite of the small number of epilepsy cases in those countries, the lack of medical professionals and advocacy might in part account for this phenomenon. These above-mentioned differences are reflected in the answers to questions concerning epilepsy-related organisations, epilepsy specialists, number of hospital beds for epilepsy, diagnostic procedures, human resources, financing, etc. Among these answers, the number of hospital beds and professionals in epilepsy care should be considered together with the magnitude of the country population.

Much attention should be paid to improving epilepsy services in developing countries. The survey shows that insufficient epilepsy services, including infrastructure, human resources, hospital beds, diagnostic equipment, AEDs, referral system, information system, training of professionals, financing, etc. exist in most of the developing countries in the Western Pacific Region. The shortage of epilepsy specialists (neurologists and neurosurgeons) means that epilepsy care is left to general practitioners, nurses or lay public health workers. The latter face difficulties in diagnosis, selecting methods of treatment, AED use, patient follow-up, etc. The public health professionals are also concerned about the large treatment gap in rural areas. It is estimated that 70% to 90% of people with epilepsy are not treated properly or are not receiving any treatment at all [28].

In most developing countries in the Region, discrimination in education, employment, social relationship, marriage, etc. are commonly found. Lack of understanding of epilepsy has

undoubtedly resulted in an intensification of the stigma associated with the disorder. As shown in this survey, major problems encountered by people with epilepsy are personal difficulties in education and employment, stigma, problems concerning marriage, etc. Although they have elements in common, the scale and nature of the problems is very different in developed and developing countries. Other major difficulties facing people with epilepsy are access to epilepsy care services and AEDs, and financial difficulties such as lack of health insurance, high cost of new AEDs, etc.

This survey did not specially investigate the epidemiological data for epilepsy. However, from 12 countries that provided an estimated total number of people with epilepsy of around nine million individuals (Table 10), one may gauge a rough prevalence (for the total population of the 12 countries: 1 493 700 000) for epilepsy in those 12 countries as a whole as 5.9 per 1000 population. From the investigation of the "causes" of epilepsy, the most common are head injury, intracranial infection and perinatal factors. From these causes, one can conclude that at least some epilepsies are preventable.

Less than half the countries included in this survey have an information collection system for epilepsy. The lack of data makes it difficult to evaluate the magnitude of the epilepsy burden in most of the countries in the Western Pacific Region. This is why the GCAE activities in the Region emphasise strengthening epidemiological studies.

Last but not least, the role played by governments in the delivery, financing and management of epilepsy services and programmes should be discussed. The epilepsy-related policymaking, legislation, health insurance and other financial support, as well as infrastructure, community education, professional training, supply of AEDs, social welfare, etc. are all dependent upon governments' decisions. Most of the commonly used AEDs such as Phenytoin and Phynobarbital are not expensive in any country. If they are made available to people with epilepsy and if basic epilepsy-related training is provided to public health workers, a major proportion of people with epilepsy could have their epilepsies controlled.

4. A call to further action

4.1 Objectives

This call for action is addressed to:

- the governments of the Member States in the Western Pacific Region; and
- international and regional governmental and nongovernmental organisations in the Western Pacific Region.

We call upon you to implement and support actions in the following six areas:

(1) Public education

(2) Community based control and prevention programmes

(3) Legislative reform

(4) Investment in research

(5) Lay and professional epilepsy organisations

(6) Information exchange and intercountry cooperation.

4.2 Actions to be taken

Difficult dilemmas and choices face developing countries in bringing epilepsy "out of the shadows", as they do in all public health endeavours [30]. Of the many public health priorities that confront governments, we argue that epilepsy stands out strategically in that fairly modest effort and expenditure is likely to have a substantial impact on health. The following are recommended as priority areas for action:

(a) Strengthen public education activities concerning epilepsy

Education plays a key role in increasing public and professional knowledge about epilepsy as a treatable brain disorder and in reducing, and ultimately preventing, social exclusion of people with epilepsy. Education is needed on multiple levels to reach all those involved in epilepsy management, especially grassroots public health workers, the people with epilepsy themselves, their relatives and the general population.

Educating *community leaders* about epilepsy will lead to an increase in epilepsy cases being diagnosed and treated at primary health centres. It is particularly important to increase the awareness of epilepsy within low-income communities and to reach "hidden" people with epilepsy. The need for educating *people with epilepsy* and for incorporating an adequate knowledge of epilepsy in *school curricula* cannot be overemphasized.

The core messages of public education materials need to be refined. There is already a lot of material available for epilepsy education. However, much of it is unsuitable outside its country of origin. Suitable materials need to be developed that are tailored to the needs of individual countries and to sub-populations and sub-cultures within those countries.

(b) Improve community-based epilepsy services

In developing countries, epilepsy requires a deliberate, sustained, skilled effort by health workers, especially at the community level, to enhance access to regular treatment and to motivate patients to continue treatment. Community-based health workers also require access to specialist consultation and support. Although effective new drugs have recently come on to the market, their high cost means that poor countries often cannot afford them. However, alternative effective and affordable methods are available to control epilepsy in many patients, such as older and less expensive medications.

The responsibility for the treatment of patients with epilepsy by primary care physicians will continue to increase. At the same time, there has been an explosion of new information about the diagnosis, evaluation, natural history, and neurobiology of epilepsy. New medical and surgical treatments are being introduced at an accelerating pace.

Comprehensive treatment programmes for children with epilepsy must include evaluation and treatment of co-existing learning, cognitive, and behaviour problems, as well as family education to prevent excessive parental anxiety and overprotection, on the one hand, or emotional abuse or rejection on the other. Emphasis should be put on maternal and childhood health care, especially perinatal health services.

The ongoing demonstration projects in China and some other countries can serve as models for projects in other developing countries.

(c) Promote reform of epilepsy-related legislation

We suggest that the governments of the Member States in the Western Pacific Region review and/or legislate proper laws concerning epilepsy to protect the human rights of people with epilepsy and to prohibit discrimination in education, employment, marriage, reproduction, driving regulations or sports.

(d) Increase investment in epilepsy research

For many countries in the Western Pacific Region, especially developing countries, basic epidemiological data on epilepsy are not yet available. Therefore, *epidemiological research* is an essential first step, including surveys to establish prevalence, incidence, disability and mortality,

as well as analytical studies examining causal hypotheses, as well as disease-oriented epidemiology, social and cultural epidemiological studies of epilepsy-related attitudes and behaviour are vital. The understanding gained from such studies will serve to inform policy and public health strategies. *Genetic research* may be carried out as well if the techniques and facilities are available; this is only one of several areas of potentially fertile inter-country collaboration.

Other important areas include: research on *public health strategies*; clinical research on *diagnosis, treatment, and rehabilitation*; and scientific investigation of *traditional medicine* approaches to epilepsy treatment.

(e) Promote the establishment of epilepsy-related organisations

Strengthening local and national level organisations will help to motivate health workers and the public to improve health services for people with epilepsy and to prevent serious complications. Such organisations include professional societies, charitable foundations, epilepsy centres, and associations of patients and their families. In some developed countries, lay organisations, run by patients and their families, have been exceptionally effective in education and support, in advocacy for epilepsy issues, and can also be very useful in facilitating medical and public health research.

(f) Improve information exchange and strengthen international co-operation

Modern information technologies facilitate the rapid collection and exchange of information. Inter- and within-country information exchange through the Internet and other media should be exploited fully.

The co-organizers of the GCAE, namely, ILAE, IBE and WHO will be partners with the Western Pacific Region Member States in developing and strengthening epilepsy programmes. They can provide information, technical support and other forms of collaboration.

Finally, there is a vital role for support from other international, regional, inter-governmental and nongovernmental organisations and from the private sector.

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Appendix 1

WHO Western Pacific Region countries: Key demographic indicators

Country/area	Area (in 1000 sq. km.)	Population					
		Year	Total ('000s)	Year	Urban (%)	Year	Growth rate (%)
American Samoa	0.20	2001p	59.59	2001	53.20	1999	2.78[a]
Australia	7 692.02	2002	19 707.19	2002	84.00	2001-2002	1.14
Brunei Darussalam	5.77	2001p	345.00	2001	72.80[b]	1999-2000	2.30
Cambodia	181.04	2001	13 099.47	2001	16.00	2001	2.49[b]
China	9 596.96	2002p	1 284 530.00	2002p	39.10	1998	0.96[a]
Cook Islands	0.24	2001p	18.03	2001	67.71	2001	0.71
Fiji	18.27	2001p	821.00	2001	50.20	2001p	1.36[a]
French Polynesia	3.52	2002p	244.17	2001	52.60	2000	1.58[a]
Guam	0.55	2002p	161.28	2000	84.00[b]	1990-2000	1.51[b]
Hong Kong (China)	1.10	2002	6 787.00	2001	94.68[b]	2002	0.90
Japan	377.88	2001	127 291.00	2001	78.90	1995-2000	0.20
Kiribati	0.70	2002p	91.61	2001	38.60	2000-2001	2.20
Lao People's Democratic Republic	236.80	2001	5 377.00	2001	19.70	2000-2005	2.33
Macao (China)	0.03	2001	436.69	2001	100.00	2001	1.20
Malaysia	330.24	2002	24 530.00	2000	61.99	2001	2.20
Marshall Islands	0.20	2002p	53.75	2001	66.00	1988-1999	1.50
Micronesia, Federated States of	0.70	2002p	123.10	2001	28.60	2000	0.30
Mongolia	1 566.60	2002	2 458.96	2002	57.20	2002	1.20
Nauru	0.02	2002p	12.17	2001	100.00	2000-2001	2.10
New Caledonia	18.60	2001	212.70	2001	60.30	2000	1.65
New Zealand	270.69	2002	3 939.10	2001	85.90	2002	1.51
Niue	0.26	2001	1.77[b]	2001	33.10	1996	0.00
Northern Mariana Islands	0.46	2002p	72.69	2002	90.00	1999	5.60
Palau	0.49	2002p	20.32	2001	69.30	1999	2.30
Papua New Guinea	462.24	2000	5 190.79	2001	17.60	2000	3.10
Philippines	300.00	2002	79 503.68	2001	59.40	2000	2.00[b]
Pitcairn Islands	0.04	2002p	0.05	2001	0.00		...
Republic of Korea	99.46	2002	47 640.00	2001	82.50	2002	0.60
Samoa	2.94	2000	170.73	2001	22.30	2000	0.61
Singapore	0.69	2002	4 163.70	2001	100.00	2002	0.80
Solomon Islands	28.37	2002	444.56	2001	20.20	1999	2.80
Tokelau	0.01	2002p	1.52	2001	0.00	1996	-0.90
Tonga	0.75	2001	100.67	2001	36.00	2001	0.30
Tuvalu	0.03	2002	10.23	2001	53.20	2000	0.90
Vanuatu	12.19	2002p	201.56	2001	22.10	2000-2001	2.70
Viet Nam	331.11	2001	78 685.50	2001	24.80[b]	2001	1.35
Wallis and Futuna	0.26	2002p	14.78	2001	0.00	1994	1.30
WESTERN PACIFIC REGION		2002p	1 716 725.99	2000	39.00	2000-2005	0.78

... Data not available. p Preliminary
[a] Computed by WHO.
[b] Rectified data.

Year	< 15 years	> 65 years	% distribution of population aged 60 years or older by gender		Year	Crude birth rate per 1 000 population)	Crude death rate per 1 000 population)	Dependency ratio	Year 2000[d]	Total fertility rate (women 15-49 years)
			Male	Female						
2001	38.25	3.48	49.40	50.60	2000	30.20	3.91	71.08	2002	est. 3.55
2002	20.30	12.70	45.92	54.08	2001	12.50	6.60	48.66	2001	1.73
2000	32.20	3.50	50.67	49.33	2000	22.10	2.90	55.19	1999	2.70
2001	42.90	3.40	36.22	63.78	2000	27.70	(2001) 9.70	78.49	2000	4.00
2002p	22.40	7.30	47.90	52.10	2002p	12.86	6.41	46.37	2000	1.90
2001	34.62	5.51	52.44	47.62	2001	16.00	5.70	66.46	2001	2.09
2001p	33.00	4.00	47.38	52.62	1998	21.88	6.25	62.64	2000-2005	est. 3.05
2002p	32.85	3.93	49.37	50.63	2000	21.00	4.30	59.77	1999	2.50
2002p	30.79	4.25	50.76	49.25	2001	22.70	4.40	51.36	2001	2.95
2002	16.12	11.45	47.68	52.32	2002p	7.10	5.00	38.53	2001	0.93
2001	14.36	17.97	43.87	56.13	2001	9.30	7.70	46.77	2001	1.33
2002p	41.17	3.47	43.28	56.70	1999	33.00	(1995-1999) 8.00	80.52	2002	est. 3.95
2001	43.59	3.50	46.96	53.04	2000	34.00	6.30	89.62	2000	4.90
2001	21.27	7.38	44.87	55.14	2001	7.47	3.06	42.37	2000	1.25[b, c]
2001	32.60	4.00	47.44	52.56	2002p	21.80	4.40	61.67	2001	2.90
2002p	42.35	2.08	48.58	51.24	1999	41.80	4.90	82.23	2002	est. 4.55
2002p	42.54	3.59	47.67	52.35	2000	23.00	3.80	89.15	2000	4.40
2002	32.69	3.53	45.55	54.44	2002	18.80	6.07	62.83	2002	2.10
2002p	42.55	1.54	49.56	50.15	2000	est. 22.90	est. 5.10	78.27	2002	est. 3.90
2001	29.60	5.50	48.21	51.79	2000	21.60	5.10	54.89	2000	2.63
2002	22.30	11.90	45.30	54.70	2001	14.36	7.16	52.24	2001	1.97
2001	29.56[b]	8.88[b]	44.71	54.90	2000	13.40	6.40	69.34	2002	est. 2.80
2002p	25.66	1.70	52.87	47.13	1999	21.34	2.67	34.95	1999	1.95
2002p	27.89	5.49	43.21	56.79	1998	15.46	6.96	51.02	2002	est. 2.45
2000	39.97	2.37	56.21	43.79	2000	32.00	9.00	79.23	2000-2005	est. 3.85
2002	35.13	4.15	46.50	53.50	2002	25.70	5.77	67.55	2002	3.23
2002p	17.02	38.30	47.37	52.63		…	…	…		…
2002	20.60	7.90	41.70	58.30	2002	11.70	5.30	39.32	2001	1.30
2000	40.60	4.70	49.96	50.02	2000	29.10	5.50	78.14	2000	4.30
2002	21.19	7.48	46.71	53.29	2002	11.40	4.40	41.44	2002	1.37
2002	40.32	3.45	58.98	41.02	1999	34.00	9.00	102.39	1999	4.80
2002p	41.96	6.06	44.88	54.33	1996	33.10	8.20	93.53	2002	est. 4.15
2001	36.73	5.68	49.07	50.93	2001	25.10	5.70	79.49	2001	3.40
2002	32.72	6.55	39.37	60.53	2001	17.40	7.60	67.34	2001	2.52
2002p	42.15	3.20	54.81	45.20	1999	33.00	6.00	83.64	1999	4.50
2001	31.17	6.90	42.54	57.46	2001	19.67	(1999) 5.56	62.64	1999	2.33
2002p	36.40	5.25	44.34	55.75	2000	est. 28.90	est. 6.90	76.51	2002	est. 2.85
2002p	24.24	7.62	46.79	53.21	2000-2005	14.90	7.00	48.34	1995-2000	2.00

est. Estimate.
[c] Excluding non-resident labour.
[d] Dependency ratio is based on 65+ cut-off.

Appendix 2

WHO Western Pacific Region countries: Key socio-economic indicators

Country/area	Adult literacy rate*				Year	Per capita GNP (in US$)	
	Year	Both sexes (%)	Male (%)	Female (%)			
American Samoa	1990	99.50	99.50	99.50	1996	GDP	2 179
Australia	1996	80.00	…	…	2001-2002		19 958
Brunei Darussalam	2000	91.50	94.60	88.10	1999	GDP	14 687
Cambodia	2000	67.80	79.80	57.10	2000		260
China	2000	84.10	91.70	76.30	2001	GDP	913
Cook Islands	2001	100.00	100.00	100.00	2000	GDP	4 355
Fiji	2000	92.90	94.90	90.80	2001p	GDP	1 832
French Polynesia	1996	95.60	95.70	95.60	1998		13 846
Guam	1990-1995	96.40	…	…	1999		12 722[b]
Hong Kong (China)	2001	92.70	96.50	89.20	2001p		25 524
Japan	1999	99.00	…	…	2000	GDP	37 504
Kiribati	1997	…	94.00	91.00	2000	GNI	950
Lao People's Democratic Republic	2000	68.50	82.00	55.00	2000	GNI	290
Macao (China)	2001	91.30	…	…	2001	GDP	14 281
Malaysia	2000	93.80	…	…	2002p	GNI	3 631
Marshall Islands	1999	97.00	96.80	97.20	2002	GNI	1 970
Micronesia, Federated States of	2000	89.00	…	…	2000	Nominal GDP	1 934
Mongolia	2000	97.80	98.00	97.00	2001	GDP	433
Nauru	1997	…	95.00	95.00			…
New Caledonia	1996	96.20	96.80	95.50	1997		16 327
New Zealand		…	…	…	2001		13 232
Niue	1998	97.00	…	…	1999-2000	GDP	3 870
Northern Mariana Islands	1990	99.10	99.30	98.80	1998		28 734
Palau	1993	78.00	…	…	1999	GDP	7 137
Papua New Guinea	2000	56.28	62.39	49.88	2000	GNI	700[b]
Philippines	2000	95.30	95.50	95.10	2002	GDP	946
Pitcairn Islands		…	…	…			…
Republic of Korea	2000	97.80	99.10	96.40	2000p	GNI	9 628
Samoa	1999	97.40	97.60	97.50	1999	GDP	1 176
Singapore	2002	93.70	…	…	2002		20 922
Solomon Islands	1999	77.00[b]	84.00[b]	69.00[b]	1999		750
Tokelau	1991	91.16	…	…	1999		890
Tonga	2000	98.80	…	…	2000-2001		1 373
Tuvalu	1998	95.00	95.00	95.00	2000		1 296
Vanuatu	1999	74.00	…	…	2000	GNI	1 150
Viet Nam	2000	92.90	…	…	2001	GDP	419
Wallis and Futuna		…	…	…			…

… Data not available.
GNP Gross national product
[b] Rectified data.
p Preliminary
GDP Gross domestic product
*Millennium Development Goals
GNI Gross national income

Year	Health expenditure				Human development index (HDI) value 2000
	Per capita (US$ / local currency)		As % of national budget	As % of GNP	
1996	US$	435	(1998) 10.00	…	…
2000-2001	Aus$	3 153	14.57[e]	9.00 (GDP)	0.94
2000	Bru$	601	7.45[b]	(1999) 2.42 (GDP)	0.86
2002	US$	3	6.60	(1999) 0.63 (GDP)	0.54
1999	Yuan	332	…	5.10 (GDP)	0.73
1997	NZ$	253	10.70	3.20 (GDP)	(1998) 0.82
1998	FJ$	100	7.00	3.00	0.76
1997	US$	1 348	…	10.00	…
2000	US$	1 032[b]	34.80[f]	…	…
2001-2002p	US$	649	12.45	2.59	0.89
1999	US$	1 181	19.90	…	0.93
1998	Aus$	99	15.70	…	(1998) 0.52
1998-1999	US$	12	(1996) 7.60	(1998) 1.20 (GDP)	0.49
2001	US$	323	11.30	2.28 (GDP)	(1999) 0.87
2000	US$	61[b]	6.90[b]	1.70[b]	0.78
1999	US$	248	25.00	4.00 (GDP)	(1998) 0.56
2000	US$	87	6.00	…	(1998) 0.57
2002	US$	21	10.50	4.70 (GDP)	0.66
1995-1996		…	8.90	…	(1998) 0.66
1999	Francs	1 149	…	9.22 (GDP)	…
2001	US$	761	19.23	5.75	0.92
2000	US$	406	7.80	…	(1998) 0.77
2000	US$	519	…	…	…
1997	US$	633	…	7.00	(1998) 0.86
2000	US$	19	13.00	3.90	0.54
2000	PHP	1 486	7.10	3.25	0.75
		…	…	…	…
2001	US$	(1999) 207	7.52	(2000) 1.03 (GDP)	0.88
1998-1999	US$	82	17.00	6.60 (GDP)	0.72
2001	S$	480	5.70	0.90 (GDP)	0.89
1999	SI$	(1996) 28	17.00	(1996) 4.90 (GDP)	0.62
1999-2000	NZ$	341	8.20	…	…
2001-2002	US$	est. 48	est. 11.00	…	(1998) 0.65
2002	Aus$	(1998) 141	0.80	(1998) 7.10	(1998) 0.58
2001	US$	76	10.30	…	0.54
2001	VND	78 600[b]	5.00	1.28 (GDP)[b]	0.69
		…	…	…	…

est. Estimate.

[e] Percent of budget is for government only.

[f] Budget applies to public health, mental health departments and local hospital.

Country/area	% of population with*				Estimated smoking prevalence among adults			Suicides (per 100 000 people)	
	Year	Access to safe water (%)	Year	Adequate excreta disposal facilities (%)	Year	Male (%)	Female (%)	Male (1998-2000)	Female (1998-2000)
American Samoa	2000	100.00	1999	98.00	1985	41.00	16.20	...	...
Australia	2000	100.00	2000	100.00	1998	29.90	24.20	21.20	5.10
Brunei Darussalam	1996	98.00	1996	79.00	1997	36.10	6.40	...	...
Cambodia	2000	31.00	2000	21.00	1999	66.00 (Urban)	8.00	...	...
China	2000	75.00	2000	38.00	1996	66.90	4.20	13.40	14.80
Cook Islands	2001	100.00	2001	100.00	1998	34.40	71.10	...	...
Fiji	2000	47.00	2000	43.00	1988	50.50-59.30	13.99-30.60	...	...
French Polynesia	2000	100.00	2000	98.00	1995	36.00	36.00	...	...
Guam	2002	100.00	2002	100.00	1999	37.70	26.90	...	...
Hong Kong (China)	2001	99.90	2001	> 99.00	1998	27.10	2.90	16.70	9.80
Japan	2000	96.40	1996	97.90	1999	49.20	10.40	36.50	14.10
Kiribati	2000	47.00	2000	48.00	1999	56.50	32.30	...	...
Lao People's Democratic Republic	2000	52.00[b]	2000	37.30[b]	1995	41.00	15.00	...	...
Macao (China)	2000	100.00	1999	99.85	1997	31.58	4.18	...	...
Malaysia	2001	92.10	2001	99.60	1986	41.00	4.00	...	...
Marshall Islands	1999	88.00	1999	81.30		...	...	...	...
Micronesia, Federated States of	2000	41.00	2000	est. 45.00		...	...	...	...
Mongolia	2000	60.00	2000	30.00	1997	55.00	19.00	...	...
Nauru		...		...	1975	53.00	59.00	...	...
New Caledonia	1996	100.00	1996	90.30	1992	28.00	34.00	...	...
New Zealand	2000	86.00		...	1999	26.00	25.00	23.70	6.90
Niue	2001	100.00	2001	100.00	1980	58.00	17.00	...	...
Northern Mariana Islands	1999	100.00	1999	90.00		...	...	...	...
Palau	2000	79.00	2000	100.00	1997	18.10% (no gender breakdown)		...	...
Papua New Guinea	2001	41.00	2001	83.00	1990	46.00	28.00	...	...
Philippines	2000	87.00	2000	83.00	1999	53.80	11.00	...	...
Pitcairn Islands		...		...		...	...	...	...
Republic of Korea	2000	87.10	2000	70.50	1997	65.00	4.40	18.80	8.30
Samoa	2000	99.00	2000	99.00	1994	33.90	12.70	...	...
Singapore	2001	100.00	2001	100.00	1998	26.90	3.10	12.50	6.40
Solomon Islands	2000	71.00	2000	34.00	1989	...	23.00	...	...
Tokelau	2000	48.00	1999	48.00	1991	67.60	42.00	...	...
Tonga	2001	97.00	2001	94.00	1991	64.80	13.00	...	...
Tuvalu	2001	100.00[b]	1999	100.00[b]	1976	51.00	31.00	...	...
Vanuatu	2000	88.00	2000	100.00	1998	49.00	5.00	...	...
Viet Nam	2001	51.80	2001	50.50	1997	50.00	3.40	...	...
Wallis and Futuna	2000	100.00	2000	80.00	1996	42.00	18.00	...	...

est. Estimate
... Data not available.
[b] Rectified data.
* Millennium Development Goals

Appendix 3

WHO Western Pacific Region countries: Key data on epilepsy

Notes:

Abbreviations: n.a. = not available.

Explanatory note re "Epilepsy professionals": in the Questionnaire on Country Resources, the question was asked as follows: "What number of the following professionals are involved *for 50% or more of their time* in epilepsy care?" Thus, for example, although Japan has many neurologists, apparently none meet this criterion.

Currency: $ and ¢ refer to currency of the United States, unless otherwise indicated.

AMERICAN SAMOA

- Epilepsy data not yet available

AUSTRALIA

- Epilepsy professionals: neurologists, neurosurgeons, neuropsychologists, neurophysiologists, social workers, psychiatrists, neurological nurses, psychologists.
- Epilepsy equipment, facilities etc: CAT, MRI, PET, SPECT, EEG, video-EEG monitoring, epilepsy surgery, including intracranial electrophysiology.
- Epilepsy associations: Epilepsy Society of Australia; Epilepsy Australia; Epilepsy Foundations in various states.
- Major causes of seizures: hippocampal sclerosis, post-traumatic, stroke, perinatal injury, idiopathic.
- Available antiepileptic drugs (and cost): acetazolamide, clobazam, clonazepam, diazepam, ethosuximide, gabapentin, lamotrigine, levetiracetam, nitrazepam, oxcarbazepine, phenobarbitone, phenytoin, primidone, sulthiame, tiagabine, topiramate, valproate, vigabatrin. Most of these are subsidized under a national Pharmaceutical Benefits Scheme (PBS) which limits the cost to AU$ 23 per month's supply (AU$ 3.70 for "concessional patients", e.g. disability pensioners).

BRUNEI DARUSSALAM

- Epilepsy data not yet available.

CAMBODIA

- Epilepsy professionals: Neurologists only.
- Epilepsy equipment, facilities etc: No neuroimaging or EEG. Psychiatric counselling.
- Epilepsy associations: Nil.
- Major causes of seizures: Head trauma, cerebral atherosclerosis, stroke, encephalitis, brain tumour.
- Available antiepileptic drugs (and cost): Phenobarbital 100mg US$ 0.10, Phenytoin 100mg US$ 0.1, Valproic acid 500mg US$ 0.15, carbamazepine 200mg US$ 0.15, clonazepam 2mg US$ 0.10.

CHINA

- Epilepsy professionals: Specialist neurologists, neuro-paediatricians, psychiatrists, neurosurgeons, neurological nurses, psychologists, social workers, education specialists.
- Epilepsy equipment, facilities etc: CAT, NMR, EEG, therapeutic drug monitoring, long-term video/EEG monitoring, epilepsy surgery, neuropsychological services, psychiatric counselling, special education.
- Epilepsy associations: Epilepsy Group of Chinese Neurological Society; Beijing Anti-Epilepsy Association, The Home of Epilepsy.
- Major causes of seizures: Prenatal causes: genetic factors, Perinatal causes: brain asphyxia, brain injury during labour, head injury, encephalitis or meningitis, cysticercosis.
- Available antiepileptic drugs (and cost): Phenytoin 100mg, 0.044 yuan, Phenobarbital 30mg, 0.02 yuan, Carbamazepine 100mg, 0 .092 yuan, Tegreton 200mg, 1.42 yuan, Valproate 200mg, 0.134 yuan, Depakine 500mg, 3.467 yuan, Topiramate 25mg, 1.45 yuan. Lamotrigine also available.

COOK ISLANDS

- Epilepsy professionals: No specialist epilepsy workers, some social work and psychiatric nurse care.
- Epilepsy equipment, facilities etc: No neuroimaging or EEG. Some psychiatric counselling, social rehabilitation, and special education available.
- Epilepsy associations: Are Pa Taunga (Richmond Foundation).
- Major causes of seizures: Idiopathic, post-traumatic, birth related injury/insult, hippocampal sclerosis, brain infection.
- Available antiepileptic drugs (and cost): Phenytoin 100mg $ 0.02,Carbamazepine 200mg $ 0.03, Sodium Valproate 200mg $ 0.30, Phenobarbital 30mg $ 0.03, Diazepam inj.10mg/2ml $ 0.43. Limited availability of topiramate and lamotrigine.

FIJI

- Epilepsy professionals: No epilepsy specialists.
- Epilepsy equipment, facilities etc: CT, therapeutic drug monitoring, EEG machine (but no-one trained to read EEGs), psychiatric counselling.
- Epilepsy associations: Nil.
- Major causes of seizures: Idiopathic, head injury, cerebrovascular disease (stroke), birth asphyxia, neoplastic.
- Available antiepileptic drugs (and cost): Carbamazepine, 9 cents; phenytoin 100mg, 6 cents; phenobarbitone 60mg, 2 cents; sodium valproate , 15 cents; primidone, 7 cents. Also available: ethosuximide, diazepam injection.

FRENCH POLYNESIA

- Epilepsy professionals: No epilepsy specialists.
- Epilepsy equipment, facilities etc: CT but no MRI or EEG. Psychiatric counselling and social rehabilitation.
- Epilepsy associations: Nil.
- Major causes of seizures: Essential, traffic accidents, tumours, vascular accidents, neonatal accidents.
- Available antiepileptic drugs (and cost): Valproate, valpromide, carbamazepine, phenobarbital, benzodiazepine. Costs n/a.

GUAM

- *Epilepsy data not yet available.*

HONG KONG (CHINA)

- *Epilepsy data not yet available.*

JAPAN

- Epilepsy professionals: Many health professionals, but few specialized in epilepsy. 200 neurological nurses doing largely epilepsy work, also some psychologists, social workers and education specialists.
- Epilepsy equipment, facilities etc: CT, NMR, PET, SPECT, MEG, therapeutic drug monitoring, long-term video/EEG monitoring, epilepsy surgery, neuro-psychological services, psychiatric counselling, social rehabilitation, special education, sheltered work.
- Epilepsy associations: Japan Epilepsy Society; Japan Epilepsy Organization.
- Major causes of seizures: Unknown, perinatal accident, central nervous system infection, cerebral malformation, initial convulsive status.
- Available antiepileptic drugs (and cost): Phenytoin, phenobarbital, carbamazepine, valproate, zonisamide, acetazolamide, primidone, clobazam, clonazepam, diazepam, nitrazepam, pivacetam. Carbamazepine 200mg,16 ¥; valproate 200 mg, 21.60 ¥; phenytoin 100 mg,10.7 ¥; zonisamide 100 mg, 48 ¥; phenobarbital 30 mg, 6 ¥.

KIRIBATI

- *Epilepsy data not yet available.*

LAO PEOPLE'S DEMOCRATIC REPUBLIC, THE

- Epilepsy professionals: One neurologist.
- Epilepsy equipment, facilities etc: CT, EEG, psychiatric counselling.
- Epilepsy associations: Nil.
- Major causes of seizures: Idiopathic, perinatal problem, encephalitis, cerebral trauma, cysticercosis.
- Available antiepileptic drugs (and cost): Phenobarbital 100mg, 200kip (0.025$); diazepam 5mg, 200kip (0.025$); clonazepam 2mg,1000 kip (0.15$); carbamazepine 200mg, 2000kip (0.25$); valproate (Depakine) 200mg, 2000kip (0.25$).

MACAO (CHINA)

- *Epilepsy data not yet available.*

MALAYSIA

- Epilepsy professionals: neurologists, paediatric neurologists, neuro-surgeon, psychologist.
- Epilepsy equipment, facilities etc: CT, NMR, EEG, therapeutic drug monitoring, long-term video/EEG monitoring, epilepsy surgery, neuropsychological services, psychiatric counselling.
- Epilepsy associations: Malaysian Society of Epilepsy; Malaysian Society of Neurosciences, epilepsy chapter.
- Major causes of seizures: Idiopathic, post-traumatic, birth related injury/insult, hippocampal sclerosis, brain infection.
- Available antiepileptic drugs (and cost): Phenytoin (100mg), 4¢; carbamazepine (200mg), 20¢; valproate (200mg), 20¢; lamotrigine (50/100mg)(RM2.52/4.13); topiramate (50mg), (RM2.86); gabapentin (300mg), (RM2.37); phenobarbitone (30mg), 2¢; clonazepam (0.5/2mg), (22/24¢). Often price of consultation includes medication and investigations including drug monitoring.

MARSHALL ISLANDS, THE

- Epilepsy professionals: Nil.
- Epilepsy equipment, facilities etc: Nil.
- Epilepsy associations: Nil.
- Major causes of seizures: Unknown.
- Available antiepileptic drugs (and cost): Unknown.

MICRONESIA, THE FEDERATED STATES

- Epilepsy professionals: One psychologist.
- Epilepsy equipment, facilities etc: No neuroimaging or EEG. Some special education.
- Epilepsy associations: Nil.
- Major causes of seizures: Meningitis, traffic accidents, falls & childhood accidents, high-fever complications, birth defects.
- Available antiepileptic drugs (and cost): Phenytoin, carbamazepine, phenobarbital. Costs n/a.

MONGOLIA

- Epilepsy professionals: Neurologists (2), neuro-paediatrician, psychiatrists (3).
- Epilepsy equipment, facilities etc: CT, EEG. Neuropsychology and psychiatric counselling.
- Epilepsy associations: Nil.
- Major causes of seizures: Neuroinfection, congenital and perinatal factors (hypoxia-asphyxia, trauma), head trauma, neurooncological and neurodegenerative diseases, cerebrovascular diseases (stroke, vascular encephalopathy).

- Available antiepileptic drugs (and cost): Carbamazepini US$ 0.1, Finlepsini 0.15 US$, Benzonali, US$ 0.05, Phenobarbital US$ 0.05, Seduxeni US$ 0.33.

NAURU

- *Epilepsy data not yet available.*

NEW CALEDONIA

- Epilepsy professionals: *Epilepsy data not yet available.*

NEW ZEALAND

- Epilepsy professionals: Nil doing >50% epilepsy work, but neurologists, neuro-paediatricians, neurosurgeons, psychiatry, neuropsychology, social work, and education specialists are available.
- Epilepsy equipment, facilities etc: CT, NMR, EEG, SPECT.
- Epilepsy associations: Epilepsy New Zealand.
- Major causes of seizures: Motor vehicle accident, birth injury, idiopathic, hormonal/biochemical imbalance.
- Available antiepileptic drugs (and cost): Phenytoin $ 0.03 average; carbamazepine $ 0.18; sodium valproate $ 0.31 average; lamotrigine $ 2.79; topiramate $ 0.83 average. Also available: ethosuximide, phenobarbitone, clonazepam, clobazam, vigabatrin, gabapentin.

NIUE

- Epilepsy professionals: Nil.
- Epilepsy equipment, facilities etc: Nil.
- Epilepsy associations: Nil.
- Major causes of seizures: post-infection, i.e. meningitis, benign febrile convulsion, traumatic.
- Available antiepileptic drugs (and cost): Carbamazepine, 0.3; sodium valproate, 0.58; phenytoin 100mg, 0.09; phenytoin 30 mg, 0.09; phenobarbitone, 0.1.

NORTHERN MARIANA ISLANDS

- *Epilepsy data not yet available.*

PALAU

- Epilepsy professionals: Nil.
- Epilepsy equipment, facilities etc: CT, plain X-ray, no EEG, TDM, psychiatric counselling.
- Epilepsy associations: Nil. Major causes of seizures: Post-head injury, idiopathic, febrile, association with alcohol and other drugs.
- Available antiepileptic drugs (and cost): Dilantin, 15¢; Tegretol 4¢; Phenobarb 0.005¢; Valium 6¢; Valproic acid 13¢.

PAPUA NEW GUINEA

- Epilepsy professionals: Nil.
- Epilepsy equipment, facilities etc: Nil except one CT scanner in private sector.
- Epilepsy associations: Nil.
- Major causes of seizures: Idiopathic - grand mal (generalized) form, cerebral palsy, post-meningitis, head injury.
- Available antiepileptic drugs (and cost): Phenytoin 100 tabs/K0.85; carbamazepine 100 tabs/K2.53; sodium valproate 100 tabs /K7.25. Also available: phenobarbitone, clonazepam.

PHILIPPINES, THE

- Epilepsy professionals: Specialist neurologists, neuro-paediatricians, psychiatrists, neurosurgeons, psychologists.
- Epilepsy equipment, facilities etc: CT, NMR, EEG, therapeutic drug monitoring, long-term video/EEG monitoring, epilepsy surgery, neuropsychological services, psychiatric counselling, special education.
- Epilepsy associations: Philippine League Against Epilepsy, Philippine Neurological Association, Child Neurology Society of the Philippines, Philippine Foundation for Epilepsy, Epilepsy Support Group of Cebu.
- Major causes of seizures: cerebrovascular accidents, central nervous system infection (TB meningitis, bacterial meningitis), head injury, brain tumours, perinatal insults/injuries.
- Available antiepileptic drugs (and cost): Phenobarbital, Php1.75; phenytoin, Php18.00; carbamazepine, Php16.00; valproate, Php18.00; lamotrigine, Php27.00. Also available: gabapentin, topiramate, clonazepam, diazepam.

REPUBLIC OF KOREA, THE

- Epilepsy professionals: Specialist neurologists, neuro-paediatricians, psychiatrists, neurosurgeons, neurological nurses, psychologists.
- Epilepsy equipment, facilities etc: CT, NMR, EEG, SPECT, PET, therapeutic drug monitoring, long-term video/EEG monitoring, epilepsy surgery, neuropsychological services, psychiatric counselling, special education.
- Epilepsy associations: Korean Epilepsy Society, Korean Epilepsy Association.
- Major causes of seizures: Developmental lesions, traffic accident, cerebrovascular, CNS infections (including viral, bacterial, tuberculosis, parasites), tumour.
- Available antiepileptic drugs (and cost): Carbamazepine (200mg), $0.15; valproate (500mg), $0.2, phenytoin (100mg), $0.013; topiramate (100mg), $1.31; vigabatrin (500mg), $0.55. Also available: phenobarbital, primidone, lamotrigine, zonisamide, vigabatrin, gabapentin, oxcarbazepine, ethosuximide, clobazam, clonazepam, lorazepam.

SAMOA

- Epilepsy professionals: Nil.
- Epilepsy equipment, facilities etc: Nil.
- Epilepsy associations: Nil.
- Major causes of seizures: Idiopathic (most common), head injury, stroke.
- Available antiepileptic drugs (and cost): Phenytoin, carbamazepine, valproate (Epilian), diazepam. Costs n/a.

SINGAPORE

- Epilepsy professionals: Specialist neurologists, neuro-paediatricians, neurological nurses, social workers.
- Epilepsy equipment, facilities etc: CT, NMR, EEG, SPECT, MRI, therapeutic drug monitoring, long-term video/EEG monitoring, epilepsy surgery, neuropsychological services, psychiatric counselling.
- Epilepsy associations: Singapore Epilepsy Society (Singapore Chapter of ILAE), Singapore Epilepsy Foundation (Singapore Chapter of IBE), Epilepsy Care Group (Friends of IBE).
- Major causes of seizures: Post-traumatic, post-cerebrovascular accident, CNS infections, mesial temporal sclerosis, tumours.
- Available antiepileptic drugs (and cost): Phenytoin, 9 cents per 100mg; Phenobarbiton, 3 cents per 30mg; Carbamazepine (reg.), 9 cents per 200mg; Valproate (reg.), 24 cents per 200mg; Diazepam, 3 cents per 5 mg. Also available: topiramate, lamotrigine, gabapentin, clonazepam, clobazam, lorazepam, levetiracetam, primidone.

SOLOMON ISLANDS

- Epilepsy professionals: Nil.
- Epilepsy equipment, facilities etc: EEG. Psychiatric counselling, social rehabilitation, special education.
- Epilepsy associations: Nil.
- Major causes of seizures: Road traffic accident, psychiatric disorders, temporal lobe epilepsy seizing sufferers, emotional disorders, unequivocal epilepsy associated with schizophrenia.
- Available antiepileptic drugs (and cost): Carbamazepine, phenytoin, phenobarbitone, diazepam.

TOKELAU

- Epilepsy professionals: Nil.
- Epilepsy equipment, facilities etc: Nil except therapeutic drug monitoring.
- Epilepsy associations: Nil.
- Major causes of seizures: Direct blow (injury) to the head, traffic accident.
- Available antiepileptic drugs (and cost): Phenytoin. Cost n/a.

TONGA

- Epilepsy professionals: Nil.
- Epilepsy equipment, facilities etc: Nil.
- Epilepsy associations: Nil.
- Major causes of seizures: Idiopathic, post-meningitis, head injury, hypothalamic episode, brain tumours.
- Available antiepileptic drugs (and cost): Carbamazepine, sodium valproate, diazepam, phenobarbitone, phenytoin, clonazepam. Cost n/a.

TUVALU

- *Epilepsy data not yet available.*

VANUATU

- Epilepsy professionals: Nil specializing in epilepsy.
- Epilepsy equipment, facilities etc: Nil.
- Epilepsy associations: Nil.
- Major causes of seizures: Idiopathic, e.g. family history (most common), trauma to head (accidents and injuries), Pyrexia (febrile convulsions in children), intracranial mass lesions, encephalitis and other inflammatory conditions of brain.
- Available antiepileptic drugs (and cost): Phenytoin, carbamazepine, sodium valproate.

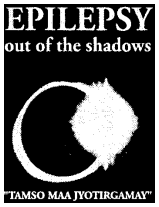
VIET NAM

- Epilepsy professionals: Specialist neurologists, neuro-paediatricians, psychiatrists, neurosurgeons.
- Epilepsy equipment, facilities etc: CT, NMR, EEG, angiography, psychiatric counselling, social rehabilitation, special education.
- Epilepsy associations: Nil.
- Major causes of seizures: Viral encephalitis, mostly Japanese encephalitis; congenital encephalopathy; parasitosis, especially neurocysticercosis and malaria; head trauma, particularly cranial injury and birth trauma; cerebral tumours.
- Available antiepileptic drugs (and cost): Phenobarbital 0,10g,VND 100; phenytoin 0.10g,VND 140; Carbamazepine 0,20g,VND 2600; valproate 0,30g, VND 1800. Also available: clonazepam, oxcarbazepine, clorazepate, diazepam.

WALLIS AND FUTUNA

- Epilepsy data not yet available.

Appendix 4



ASIAN-OCEANIAN DECLARATION ON EPILEPSY
NEW DELHI - NOVEMBER 13, 2000

A meeting "Epilepsy: A Public Health Priority in Asian and Oceanian Region" was held in New Delhi on November 10, 2000. Over 600 professionals from health and social sciences sectors and representatives from many other organizations of the region unanimously agreed on November 13, 2000 to the following declaration:

CONSIDERING THAT IN ASIA/OCEANIA:

- At least 30 million people have the common brain disorder - epilepsy. This compares with approximately 50 million people with epilepsy worldwide.
- Epilepsy can have serious medical, psychological, social and economic consequences for people with epilepsy and their families.
- Epilepsy affects people with epilepsy and their families irrespective of race, religion, gender, age or socio-economic status.
- Although epilepsy is a brain disorder, it is often mistakenly believed to be a mental illness, or to be caused by supernatural powers.
- It is erroneously, yet widely, believed that epilepsy is an infectious disease and seizures are contagious.
- It is often not realised that epilepsy is treatable, and that most people with epilepsy can lead productive lives as a result of relatively inexpensive, cost-effective treatment.
- The majority of people with epilepsy are treated inadequately and inappropriately because of ignorance, discrimination and limited health resources.
- Good quality standard anti-epileptic drugs are not regularly available in many countries.
- Disability and mortality are greater because epilepsy is inadequately treated.
- Epilepsy impacts most severely on the period of greatest development, namely childhood, adolescence and young adulthood. Yet it is during this time of life that it is most readily and successfully treated.

- The preventable causes of epilepsy such as poor perinatal care, infectious diseases, parasitic infestations, head trauma and consanguineous marriages are particularly prevalent.
- Epilepsy has not been included in most national health care plans.

PROCLAMATION

We call on the governments and other health providers of the Asian and Oceanian region, to join us in taking strong and decisive action to meet the objectives of the Global Campaign Against Epilepsy launched by the World Health Organization (WHO), the International League Against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE).

Specifically, we urge every government in this region to:

- Educate people with epilepsy, their families and the general public about epilepsy as a widespread, non-communicable and treatable chronic brain disorder. Educational means appropriate to all levels of literacy should be used.
- Educate and train health care and other relevant professionals about epilepsy, its prevention and its treatment.
- Provide access to trained personnel, modern diagnostic equipment and appropriate medication and/or surgical treatment for epilepsy.
- Promote and support research in Asia and Oceania into the basic processes, clinical aspects, and psycho-social consequences of epilepsy.
- Promote social integration and eliminate discrimination against people with epilepsy in all spheres of life, especially school, work and marriage.
- Include epilepsy in their national health plans, just as they do maternal and child health, mental health, infections and immunization.
- Encourage cooperation between modern medical, traditional and other healing systems for the treatment of epilepsy.
- Encourage the public and private sectors, as well as relevant nongovernmental organizations to actively support local activities related to the Global Campaign Against Epilepsy.
- Raise public awareness of epilepsy by proclaiming a National Epilepsy Day, and supporting the establishment of a World Epilepsy Day.
- Encourage regional and global cooperation in dealing with epilepsy.

IBE WHO ILAE

Appendix 5

GLOBAL CAMPAIGN AGAINST EPILEPSY
World Health Organization
International League Against Epilepsy
International Bureau For Epilepsy

*A questionnaire on country resources for epilepsy**

Country name: .....

Filled by: .....

Name .....

Current position .....

Connection with epilepsy .....

Address .....

Telephone .....

Fax .....

Email .....

Filled in: Date ..... Month ..... Year .....

*In the context of this questionnaire, *epilepsy* refers to all types of this disorder, epileptic syndromes and related disorders.

1. Professional association of epilepsy specialists

1.1 Is there a professional association of epilepsy specialists in the country (e.g., section, league, chapter of the International League Against Epilepsy etc.)?

Yes No

1.2 If yes, what is the name of the professional association of epilepsy specialists (if more than one, list all)?

1.3 What is the number of members in (each of) the association(s)?

1.4 What are the specific activities of the national association (s) of epilepsy specialists (tick all that apply)?

1.4.1 Recognizing or certifying specialists in epileptology

1.4.2 Organizing professional meetings and conferences on epilepsy

1.4.3 Accrediting epilepsy centres for postgraduate training in epileptology

1.4.4 Constructing curriculum for postgraduate training in epileptology

1.4.5 Publishing guidelines and recommendations on epilepsy

1.4.6 Advocacy on epilepsy-related issues

1.4.7 Advising Government on epilepsy and epilepsy-related issues

1.4.8 Other (specify).....
.....
.....

2. Other organizations dealing with epilepsy

2.1 Are there any other organizations including patient and lay associations dealing with epilepsy in the country (e.g., section of the International Bureau for Epilepsy)?

Yes No

2.2 If yes, list the names of these organizations dealing with epilepsy in the country.

2.3 Which of the following activities are these organizations involved in (tick all that apply)?

2.3.1 Awareness and advocacy[b]

2.3.2 Treatment[b]

2.3.3 Rehabilitation[b]

2.3.4 Prevention[b]

2.3.5 Education

2.3.6 Other (specify).

[b]In the context of this questionnaire: *awareness and advocacy* refer to a combination of individual and social actions designed raise awareness and to gain political commitment, policy support, social acceptance and health systems support for people with epilepsy; *promotion* is a process of enabling people to increase control over the determinants of their health and well-being and to improve it; *prevention* refers to all organized activities in the community to prevent occurrence as well as the progression of epilepsy; *treatment i*ncludes relevant clinical and non-clinical care aimed at reducing the impact of epilepsy and improving the quality of life of patients with epilepsy; *rehabilitation* refers to care given to patients with epilepsy-related disabilities to help them achieve their optimum level of functioning.

3. Causes of epilepsy

3.1 Which are the five most common causes of epilepsy (e.g., cysticercosis, traffic accidents etc.)?

3.1.1

3.1.2

3.1.3

3.1.4

3.1.5

4. Epilepsy care and services

4.1 What are the five major problems encountered by the health professionals involved in epilepsy care in the country?

4.1.1

4.1.2

4.1.3

4.1.4

4.1.5

4.2 What are the five major problems encountered by the people with epilepsy in the country?

4.2.1

4.2.2

4.2.3

4.2.4

4.2.5

4.3 Which are the five main tasks of primary care[c] workers involved in epilepsy care in the country (e.g., maintenance of drugs, follow up treatment etc.)?

4.3.1

4.3.2

4.3.3

4.3.4

4.3.5

[c] Primary care in the context of this questionnaire refers to the provision of basic preventive and curative health care to the people with epilepsy at the first point of entry into the health system. Usually this means that care is provided by a non-specialist who can refer complex cases to a higher level.

4.4 Are there any epilepsy specialists in the country?

Yes No

4.5 If yes, what are the five most important services they provide to people with epilepsy?

4.5.1

4.5.2

4.5.3

4.5.4

4.5.5

4.6 What is the total number of hospital beds in the country for:

4.6.1

4.6.2

4.6.3

4.6.4

4.7 Which of the following diagnostic procedures are accessible by the health professionals dealing with patients with epilepsy in the country (tick all that apply)?

4.7.1 Computerized axial tomography

4.7.2 Nuclear magnetic resonance

4.7.3 Electroencephalography (EEG)

4.7.4 Other (specify)

NOTE: These investigations are available in the major cities and are only accessible to the small group of wealthy people who can afford private health care. For the vast majority, there are only EEG machines in some rural hospitals.

4.8 What types of sub-specialized epilepsy services are available in the country (tick all that apply)?

4.8.1 Therapeutic drug monitoring

4.8.2 Long-term video/EEG monitoring

4.8.3 Epilepsy surgery

4.8.4 Neuropsychological services

4.8.5 Psychiatric counselling

4.8.6 Social rehabilitation

4.8.7 Special education

4.8.8 Sheltered work

4.8.9 Other (specify)

4.9 What proportion of epilepsy services in the country are privately owned and run?

Private epilepsy services:

5. Human resources
What number of the following professionals in the country are involved for 50% or more of their time in the epilepsy care?

5.1 Specialist neurologists

5.2 Neuro-paediatricians

5.3 Psychiatrists

5.4 Neurosurgeons

5.5 Neurological nurses

5.6 Psychologists

5.7 Social workers

5.8 Education specialists

5.9 Other (specify)

Community workers

Rehab workers

6. Training in epileptology

6.1 Is there postgraduate specialist training in epileptology in the country?

Yes No

6.2 If yes, what is the duration of such postgraduate specialist training in epileptology?

Number of months:

6.3 How many postgraduate students get a special recognition or certification in epileptology in the country?

Average number of recognized specialists in epileptology per year:

7. Financing and budget

7.1 Is there a separate budget for epilepsy care in the ministry of health's budget or any other official document?

Yes No

7.2 What percentage of the overall health budget of the government is spent on epilepsy care per year (if not known precisely, give the best estimate)?

7.3 How are epilepsy services financed in the country (tick all that apply)?

7.3.1 Out-of-pocket payments[d]

7.3.2 Tax-based funding[d]

7.3.3 Social insurance[d]

7.3.4 Private insurance[d]

7.3.5 Private foundations[d]

7.3.6 Other (specify).....
.....

[d]In the context of this questionnaire: *out-of-pocket payments* refer to payments made for epilepsy care by the consumer or his family; *tax-based funding* refers to money for health services raised by general taxation or through taxes earmarked specifically for epilepsy care and services; *social insurance* refers to a fixed percentage of income that everyone above a certain level of income is required to pay to a government-administered or legally imposed health insurance fund which, in return, pays for part or all of consumers' epilepsy care services; *private insurance* refers to a premium that the health care consumer voluntarily pays to a private insurance company which, in return, pays for part or all of consumers' epilepsy care services; *private foundations* refer to privately owned institutions that provide funding for or financial support to epilepsy care and epilepsy services in the country.

7.4 Are disability benefits available to the people with epilepsy-related social impairments in the country?

Yes No

7.5 If yes, specify five main disability benefits that are available in the country?

7.5.1

7.5.2

7.5.3

7.5.4

7.5.5

8. Information/data collection system

8.1 Is epilepsy included in the country's annual health reporting system[e]?

Yes No

Comments .....
.....

[e]In the context of this questionnaire *annual health reporting system* refers to the preparation of yearly reports related covering all health services functions including the use of allocated funds.

8.2 If yes, is epilepsy subclassified in the country's annual health reporting system?

Comments .....
.....

8.3 Is there any epidemiological or service data collection system[f] that includes people with epilepsy?

Yes No

Comments .....
.....

[f]In the context of this questionnaire *an epidemiological or service data collection system* refers to an organized information gathering system for service activity data, it usually incorporates incidence and prevalence rates of diseases, admission and discharge rates, number of outpatient contacts and similar.

8.4 If yes, what is the most recent estimate of the number of people with epilepsy in the country?

Number of people with epilepsy:

9. Drug and other treatments

9.1 Which antiepileptic drugs have been authorised (licensed) by the government as:

9.1.1 Over the counter antiepileptic drugs:

9.1.2 General practitioner prescription needed antiepileptic drugs:

9.1.3 Specialist prescription needed antiepileptic drugs:

9.2 Which antiepileptic drugs are included in the list of essential drugs in the country?

9.3 What is the cost in local currency of the five most frequently used antiepileptic drugs in the country? Please also indicate the rate of exchange of local currency to US Dollars:

9.3.1 Drug name..... Drug cost per unit*:.....

9.3.2 Drug name:..... Drug cost per unit*:.....

9.3.3 Drug name:..... Drug cost per unit*:.....

9.3.4 Drug name:..... Drug cost per unit*:.....

9.3.5 Drug name:..... Drug cost per unit*:.....

* In the context of this questionnaire, *drug cost per unit* refers to the price of one tablet, one pill, one capsule etc. of an antiepileptic.

9.4 Which of the following services are available free of charge or without special conditions to people with epilepsy (tick all that apply)?

9.4.1 Therapeutic drug monitoring

9.4.2 Special equipment[h]

9.4.3 Neuropsychological services

9.4.4 Psychiatric counselling

9.4.5 Special school education

9.4.6 Social rehabilitation

9.4.7 Sheltered workshop

9.4.8 Other (specify). Patients qualifying for state health care are eligible for these services, at minimal cost, in theory. But, as per previous notes, the services are not very accessible to the majority.

[h]In the context of this questionnaire, *special equipment* refers to tools such as seizure alarm, non-suffocating pillow, protective helmets and similar.

10. Comments or any other information

Please return a copy of the filled questionnaire via Email, fax or mail to:

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(Attn. Dr A. Janca)
World Health Organization
Department of Mental Health and Substance Dependence
1211 Geneva 27, Switzerland
Phone: + 41 22 791 3621
Fax: + 41 22 791 4160
Email: fontanillap@who.ch

Further Information

Further information on the Global Campaign Against Epilepsy can be obtained from:

The International Bureau for Epilepsy
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e-mail: wangx@wpro.who.int

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/resources/publications/en/#epilepsy
www.globalcampaign-epilepsy.org *(joint IBE/ILAE Campaign site)*
www.ibe-epilepsy.org
www.ilae-epilepsy.org
www.wpro.who.int

EPILEPSY
out of the shadows

A Global Campaign
Against Epilepsy