



# GLOBAL CAMPAIGN AGAINST EPILEPSY (GCAE)



## ZIMBABWE GCAE COMMITTEE REPORT

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**Editors**

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**Zimbabwe League  
Against Epilepsy**

## Foreword

A Global Campaign Against Epilepsy (GCAE) was necessary because the burden of epilepsy on individuals and communities is far greater than previously realized. The problem is too complex to be solved by individual organizations. The three leading international organizations working in epilepsy have therefore joined forces in 1997 to bring epilepsy “out of the shadows” and to improve acceptability, treatment, services and prevention of epilepsy worldwide. The Campaign is conducted by the World Health Organization (WHO) in partnership with the International League Against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE). The aims of the Campaign are to provide better information about epilepsy and its consequences and to assist governments and those concerned with epilepsy to reduce the burden of the disorder.

Epilepsy affects 50 million people worldwide. In Zimbabwe the exact prevalence is not known but it is estimated to be above 1%. This means a significant population is affected and as much the stakeholders in the fight against epilepsy embraced the Global Campaign Against Epilepsy in 1997 to reduce the burden caused by epilepsy to our country.

The objectives of the GCAE are to:

1. Increase public and professional awareness of epilepsy as a universal, treatable brain disorder;
2. Raise epilepsy to a new plane of acceptability in the public domain;
3. Promote public and professional education about epilepsy;
4. Identify the needs of people with epilepsy on a national and regional basis;
5. Encourage governments and departments of health to address the needs of people with epilepsy including awareness, education, diagnosis, treatment, care, services, and prevention.

Zimbabwe set its own objectives which are to achieve the following:

- The availability of phenobarbitone in health centres increases to 80%
- The number of people receiving AEDs regularly increases by 50%
- Knowledge and attitudes about epilepsy in the community increases by 80%
- One staff member is trained in epilepsy treatment at every health centre
- 50% of people with epilepsy feel that their quality of life has improved

An important part of activities in Zimbabwe was the demonstration project which had a study and treatment component. The study was completed and this report details the results.

This report was compiled to help the GCAE Committee in Zimbabwe to report to the government of Zimbabwe and other stakeholders what has been done so far, the results, challenges and the recommendations as well as to stimulate debate into issues around epilepsy so as to build knowledge and share ideas, strategies and mobilize resources.

It is the wish of the committee that this report makes an impact in improving the quality of life of people with epilepsy.

# Table of Contents

<i>Content</i>	<i>Page</i>
<b>Section 1</b> <b>Introduction to epilepsy</b>	<b>4</b>
What is epilepsy? Epilepsy: the Global Scenario a summary by WHO	
<b>Section 2</b> <b>Understanding the GCAE</b>	<b>5</b>
What is the GCAE What activities have taken place under the GCAE What have Africans agreed?	
<b>Section 3</b> <b>The GCAE in Africa</b>	<b>9</b>
African Declaration on Epilepsy	
<b>Section 4</b> <b>The GCAE in Zimbabwe</b>	<b>11</b>
What are its objectives in Zimbabwe? What are the recommendations?	
<b>Section 5</b> Research work: the Demonstration Project in Hwedza, Zimbabwe	<b>13</b>
<b>Section 5</b> Research work: the Demonstration Project in China	<b>16</b>
<b>Section 6</b> Research work: the Demonstration Project in Brazil	<b>20</b>
<b>Section 7</b> Research work: the Demonstration Project in Senegal	<b>24</b>
<b>Appendices</b> <b>Hwedza Study protocol</b>	<b>26</b>
<b>Planned activities GCAE Zimbabwe 2010 onwards</b>	<b>52</b>
<b>Treatment Guidelines and Treatment Chart</b>	
<b>List of References</b>	<b>53</b>

# Section 1 Introduction to Epilepsy

## What is epilepsy?

Epilepsy is a chronic non-communicable disorder of the brain. It occurs all over the world. In all areas, no less than three out of every thousand people – and in several places over 40 per thousand (4%) – are affected. Every year, among every 100 000 persons there will be 40 – 70 new cases. The symptoms of epilepsy are the seizures that occur at unpredictable moments. These may vary from frequent brief lapses of consciousness to short periods of automatic subconscious behaviour or convulsions of the whole body that make the person fall over and lose consciousness completely. Intervals between seizures or clusters of seizures may vary from less than an hour to one or two years. Even in the latter case, the consequences of having the disorder affect a person's every-day life. From the first written record in 4000 BC until the present day, myths and superstitions have been associated with epilepsy. This is one of the reasons that, in many parts of the world, living conditions for people with epilepsy are far worse than might be expected, given the state of knowledge about epilepsy and the means available to stop seizures and restore complete participation in society. In addition, as long as a person is likely to have seizures, the family and close friends also suffer the burden of this disorder.

## WHO basic facts about epilepsy

- Epilepsy is a chronic neurological disorder that affects people of all ages.
- Around 50 million people worldwide have epilepsy.
- Nearly 90% of the people with epilepsy are found in developing regions.
- Epilepsy responds to treatment about 70% of the time, yet about three fourths of affected people in developing countries do not get the treatment they need.
- People with epilepsy and their families can suffer from stigma and discrimination in many parts of the world.

The estimated proportion of the general population with active epilepsy (i.e. continuing seizures or the need for treatment) at a given time is between 4 to 10 per 1,000 people. However, some studies in developing countries suggest that the proportion is between 6 to 10 per 1,000.

In developed countries, annual new cases are between 40 to 70 per 100 000 people in the general population. In developing countries, this figure is often close to twice as high due to the higher risk of experiencing conditions that can lead to permanent brain damage. Close to 90% of epilepsy cases worldwide are found in developing regions. Recent studies in both developed and developing countries have shown that up to 70% of newly diagnosed children and adults with epilepsy can be successfully treated (i.e. their seizures completely controlled) with anti-epileptic drugs. After two to five years of successful treatment, drugs can be withdrawn in about 70% of children and 60% of adults without relapses.

- In developing countries, three fourths of people with epilepsy may not receive the treatment they need.
- About 9 out of 10 people with epilepsy in Africa go untreated.
- Surgical therapy might be beneficial to patients who respond poorly to drug treatments.

## **Section 2      Understanding the GCAE**

### **What is the Global Campaign against Epilepsy (GCAE)?**

This is the worldwide project to deal with epilepsy. It was established in 1997 as a joint project of the World Health Organization (WHO), International League against Epilepsy (ILAE) and International Bureau for Epilepsy (IBE).

#### **Objectives:**

1. Increase public and professional awareness of epilepsy as a universal, treatable brain disorder;
2. Raise epilepsy to a new plane of acceptability in the public domain;
3. Promote public and professional education about epilepsy;
4. Identify the needs of people with epilepsy on a national and regional basis;
5. Encourage governments and departments of health to address the needs of people with epilepsy including awareness, education, diagnosis, treatment, care, services, and prevention.

#### **Mission statement:**

To improve acceptability, treatment, services and prevention of epilepsy worldwide.

#### **Campaign tactics:**

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

#### **Campaign strategy:**

Working along two parallel tracks, the Campaign seeks to:

1. Raise general awareness and understanding of epilepsy;
2. Support Departments of Health in identifying needs and promoting education, training, treatment, services, research and prevention in their countries.

### **Activities of the GCAE**

#### **1. Phase I: 1997 – 2001 Consultative Conferences**

The Global Campaign was launched with an initial focus on raising public, professional and political awareness of epilepsy. Special conferences were held in every region of the world. In Africa, the first conference was held in Harare, Zimbabwe. Regional declarations were drafted and approved identifying the scale and scope of problems and outlining actions required to deal with these.

#### **2. Phase II: 2001 – 2005 Regional declarations**

The advocacy work begun in phase I continued with the promotion of the regional declarations.

The focus of phase II was the development of demonstration projects. In summary the objectives of the demonstration projects were and still remain: –

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

### **3. Demonstration projects**

In order to assist Departments of Health which are looking for tools applicable in their country to realize the objectives of the Campaign, Demonstration Projects are organized in a number of countries in different regions. These Demonstration Projects offer models of how to identify needs; how to educate and train staff involved in diagnosis, treatment, services, prevention and research; and how to promote education of the general public. The ultimate goal of the Demonstration Projects is the development of a successful model of epilepsy control that will be integrated into the health care systems of the participating countries and regions and, finally, applied on a global level. Furthermore it is hoped that the lessons learnt from the Demonstration Projects will support the development of preventative measure strategies globally.

Demonstration projects have been successfully completed in China, Zimbabwe, Senegal and Brazil. The adoption and/or transfer of completed projects into permanent features are currently taking place. For example, the Brazilian demonstration project is being used to form a new national epilepsy program in Brazil.

### **4. Demonstration project on epilepsy surgery**

Epilepsy surgery is a safe and effective alternative treatment for a wide variety of epileptic conditions that cannot adequately be treated with AEDs. Investment in epilepsy surgery centres, even in the poorest regions, could greatly reduce the economic and human burden of epilepsy. Yet there is a marked treatment gap with respect to epilepsy surgery even in richer countries. 80% of the cost of epilepsy is due to patients whose seizures are not controlled with drugs. 80% of the burden of epilepsy is in the developing world. Most patients with surgically remediable epilepsy can now be diagnosed non-invasively with EEG and MRI. The major investment for epilepsy surgery is in appropriately trained personnel. Surgical treatment should, and can, be made available to people who live in developing countries. In view of all this, the Global Campaign is testing the feasibility of a demonstration project on surgery, possibly to be undertaken in collaboration with the World Federation of Neurosurgical Societies (WFNS).

### **5. Epilepsy Atlases**

An international epilepsy atlas was compiled. Following on from the success of the global 'Epilepsy Atlas', it is intended to develop an 'Epilepsy Atlas' for each region of the world identifying resources and gaps in more detail in individual countries.

## **6. The publication of a series of regional reports on the status of epilepsy**

## **7. The completion of guidelines on the treatment of epilepsy in childhood and adolescence**

### **6. The promotion of multicentric collaborative studies linking centres in developing and developed countries**

A number of important aspects of epilepsy research need collaborative studies that involve countries belonging to different parts of the world. Typical examples are epidemiological and genetic studies and clinical trials. The aims of this activity are:

- To identify research priorities and needs at a regional level.
- To stimulate collaborative studies involving countries with different economic situations.
- To develop guidelines and recommendations to facilitate interactions between participants.

### **8. Collaborative Research on Epilepsy and Stigma (CREST) Project – studying stigma in China and Vietnam.**

This project on stigma is a continuation of a study started in 2004. It is made possible by the United States National Institutes of Health (NIH) Fogarty foundation preparatory grant (TW-03-007). The project aims to develop culturally appropriate approaches to reduce stigma and discrimination. The results of an initial literature search guide further developments of the project, starting with ethnographic studies exploring the prevailing beliefs and attitudes to epilepsy in China and Vietnam. Using in-depth interviews and focus groups, data will be gathered from people with epilepsy, their family members, their local communities and their general and specialized healthcare workers. It is anticipated that study findings will provide insights into the dimensions of epilepsy stigma identifiable in these two countries and highlight the similarities and differences in order to gain an understanding of the following: – • Ideas held about epilepsy (explanatory models of causation, treatment, prevention).

- The impact of these ideas on attitudes toward having epilepsy.
- Ideas and practices relating to its management as a health condition.
- Ideas and practices relating to its management as a potential source of stigma.

### **9. A review of legislation worldwide and its impact on the lives of people with epilepsy**

The right to equal treatment is clearly described in international law (for example, United Nations and EU charters and treaties) and deserves the protection of enforceable legal remedies.

However, experience indicates that some laws in some countries that impact on the lives of people with epilepsy are outdated and fail to adequately promote and protect human rights. In some cases laws even actively violate rights, often due to being based on centuries of stigmatisation. Furthermore, in many countries legislation is totally absent.

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

This project on epilepsy and legislation aims to collect information on existing legislation and regulations related to epilepsy in the areas of civil rights, education, employment, residential and

community services, and provision of appropriate healthcare from countries all over the world. This information will be collated in order to review the comprehensiveness and adequacy of these legal measures in promoting and protecting the civil and human rights of people with epilepsy.

In particular the project will: –

- Identify key human rights issues that are being overlooked and that need to be addressed at national / regional levels.
- Develop an effective reference guide for professionals working in the area of epilepsy, lawyers and policy-makers as well as advocacy and human rights organisations working in the interest of people with epilepsy at national as well as international levels.
- Provide instruments for advocacy and lobbying to improve human rights conditions for people with epilepsy.
- Provide useful tools to reform laws and regulations related to epilepsy thus leading to better care and services and improved living conditions for people with epilepsy throughout the world.
- Increase awareness among people with epilepsy of the possibilities available to them for better integration into society, helping to reduce discrimination and stigma associated with epilepsy.



## Section 3      The GCAE in Africa

### African Declaration on Epilepsy

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

Considering that:

- a. Epilepsy is the most common serious chronic brain disorder, estimated to affect at least 50 million people in the world of which 10 million live in Africa alone, irrespective of race, religion, sex, age or socioeconomic groups.
- b. Epilepsy is not an infectious disease and seizures are not contagious.
- c. All people with epilepsy can be effectively and inexpensively treated.
- d.  $\frac{3}{4}$  of people with epilepsy in Africa have no access to healthcare provisions and are not appropriately treated.
- e. General information about epilepsy, trained expertise, diagnostic facilities, antiepileptic drugs and surgery are not available to – or affordable by – the majority of people with epilepsy, for geographical, financial or cultural reasons.
- f. Beliefs in supernatural causes and traditional treatment of epilepsy in Africa contribute to the under-utilization of the medical health services, to discrimination and social isolation.
- g. Because of these factors, disability and mortality are greater in Africa than elsewhere.
- h. Epilepsy has serious physical, psychological and social consequences for the affected and their families.
- i. The impact of epilepsy is most severe in children and adolescents.
- j. In Africa preventable causes of epilepsy are more frequent than elsewhere including infectious diseases, head trauma, insufficient per natal care and consanguinity.
- k. Epilepsy does not receive adequate attention in existing national health plans.

We proclaim the following:

- a. Epilepsy is a healthcare priority in Africa requiring every government to develop a national plan to:
- b. Address the needs with respect to epilepsy in terms of access to trained personnel, modern diagnostic equipment, antiepileptic medication and surgical treatment, information communication, prevention and social integration.
- c. Educate and train health care and other relevant professionals about epilepsy.
- d. Educate those affected by epilepsy and the general public about epilepsy as a universal neurological, non communicable and treatable condition.
- e. Eliminate discrimination in all spheres of life particularly at school and the work place.
- f. Encourage incorporation of prevention and treatment of epilepsy in national plans for other relevant healthcare issues such as maternal and child health, mental health, infections, head trauma, neurovascular diseases and community based rehabilitation

programs.

- g. Encourage the public and private sectors and NGOs to get involved in the local activities of the Global Campaign against Epilepsy.
- h. Promote interaction with traditional health systems.
- i. Encourage basic and applied research on epilepsy.
- j. Proclaim a National Epilepsy Day.
- k. Encourage regional and continental cooperation.

DAKAR, SENEGAL

6<sup>TH</sup> MAY 2000

## **Section 4      The GCAE in Zimbabwe**

### **What are its objectives in Zimbabwe?**

The GCAE is the single biggest strategy to deal with epilepsy in the world and many countries including Zimbabwe have adopted it as their foremost tool in improving the quality of life for people with epilepsy. With the reconstitution of the committee, we should work hard to put epilepsy on the national map. This will go a long way in addressing the health and social concerns affecting people with epilepsy and their families.

The key outcomes for all the of the Global Campaign's demonstration projects are a reduction in the treatment gap and in the burden of epilepsy. The means of gathering this data will be provided in the prevalence surveys at the beginning and end of the project and through the measures devised by the ILAE.

More specifically, the project in Zimbabwe will also seek to achieve the following:

- The availability of phenobarbitone in health centres increases to 80%
- The number of people receiving AEDs regularly increases by 50%
- Knowledge and attitudes about epilepsy in the community increases by 80%
- One staff member is trained in epilepsy treatment at every health centre
- 50% of people with epilepsy feel that their quality of life has improved

### **Activities in Zimbabwe**

Zimbabwe adopted the GCAE in 1997 and formed a committee with representatives from Ministry of Health and Child Welfare, WHO, ESF and ILAE. The committee did very well to run programmes indicated above with financial support from WHO and technical support from the College of Health Sciences (then Medical School). It is quite unfortunate the committee became inactive between 2007 and 2010 mainly due to issues related to challenges facing the economy that period.

### **Projects funded by WHO-AFRO for Zimbabwe under the GCAE**

1. The Zvimba study as discussed below
2. Production of treatment guidelines
3. Drafting of a booklet on epilepsy management for primary health care workers.
4. Training of nurses in epilepsy management in Matabeleland provinces
5. Study in Hwedza (discussed later). This was a global demonstration project.

### **The Zvimba Study**

A critical component of epilepsy care in developing countries is the training and support of primary health care workers (PHCWs), who are mainly nurses and who treat the majority of PWE in this setting. A project in the Zvimba district of Mashonaland West Province in Zimbabwe assessed the impact of PHCW training and the distribution of local language lay

literature on the total number of PWE in primary care clinics , as well as their compliance. The number of clinic attenders increased by 70%, with improved compliance after training, awareness and distribution of literature. This study used a one-day training workshop for PHCWs run by neurologists and other tertiary care professionals. As a result of this work, consultation with the MOHCW reached a consensus that diagnosis and initiation of drug therapy for epilepsy with generalised tonic- clonic seizures could be carried out by PHCNs at clinic level, if adequately trained. To this end the 2000 edition of the national formulary, EDLIZ 2000, was edited to contain instructions and guidelines to that effect. In addition the production of a separate management module in the form of a booklet was launched at a consultative meeting on February 21, 2001.

### **Other events**

- Harare hosted a consultative conference on the Campaign in 2002
- The Committee was represented by Professor Mielke and Mrs Mundada at the setting of the African Declaration on Epilepsy in Dakar, Senegal, 2002

## **Section 5      Demonstration Project in Hwedza, Zimbabwe**

### **Introduction and Situation Analysis**

Zimbabwe is a landlocked country in Southern Africa measuring 391.000 km<sup>2</sup> and with a population of 13 million. The country shares borders with Zambia. The white population is estimated to be around 40,000. The official language is English; however, the majority of the population speak Shona or Ndebele. Just over 50% of the population is in the economic active group of 15-64 years old, while 40% are under the age of 15 years. Life expectancy is 40 years (estimates vary from 37-44 years). Despite large mineral and agricultural resources, the country's economy has suffered in recent years from political instability, involvement in the war in the Democratic Republic of Congo, the AIDS pandemic (30% of antenatal clinic attendees had been shown to be HIV positive) and from outside economic pressures of multilateral organisations, such as the World Bank and the International Monetary Fund. Inflation rose from an annual rate of 32% in 1998 to 500% in 1999.

The prevalence of epilepsy in Zimbabwe at the time of the Demonstration Project in 2003 was unknown. In 1970 Levy et al reported a prevalence rate of 7.4/1000 based on a community-based survey of 17 000 rural inhabitants, but more recent studies in other African countries report an average prevalence rates of 15/1000.

The Hwedza District is a rural area that measures 2.560 km<sup>2</sup> and has a population of 90,350. At the time of the Demonstration Project the health infrastructure counted one mission hospital, one rural hospital, 4 government rural health centres and 5 district council clinics. There were 2 doctors until 2003, but during that year and in 2004 there were no doctors. There was a well developed primary health care structure with 5-10 state registered nurses, a similar number of certified nurses and 9 Environmental Health Technicians (one at each of the aforementioned hospitals, rural centres and clinics). In 2000, before the project was initiated, there were 489 patient contacts for epilepsy (multiple contacts per patient, but these were not registered by name), and 4 new patients registered that year. Thus a prevalence of 0.45/1.000 and incidence of 4.4/1.000 was indicated. It was likely that a significant treatment gap (of around 90%) existed.

### **Organizational Context and Management Structure of Research**

The project was managed by the Zimbabwe Committee of the Global Campaign Against Epilepsy. Principal investigators were appointed and a sub-committee, including the District Nursing Officer and the District Medical Officer, was set up. An administrative assistant was appointed to implement and convey decisions.

In addition to the projects described above other projects were initiated, which are (more or less) based on protocols that were developed in collaboration with and/or under the aegis of the Campaign, but with no or limited involvement of the Campaign in the execution of the projects.

### **Overall aims**

To demonstrate that it is possible to improve the quality of life of people with epilepsy in rural Zimbabwe by:

- Establishing the prevalence of epilepsy and its treatment gap in a rural area.
- Discerning the influence of epilepsy on the quality of life of people with epilepsy in such an area.
- Positively influencing the physical quality of life of these people with epilepsy through a pharmaco-economic intervention (ensuring availability and accessibility of medical care and medications).
- Positively influencing the social quality of life of these people with epilepsy through a psychosocial intervention (a health education campaign for health staff, patients and their families, and the public).

## **Methodology**

The project consists of three phases:

- Epidemiological survey
- Intervention to improve treatment
- Education

### **Epidemiological Survey**

The questionnaire used for the prevalence survey was based on the survey used in the demonstration project for China. People identified as possibly having epilepsy were evaluated by Primary Health Care Workers at the local clinics and given a confirmatory diagnosis if appropriate. One of the principal investigators randomly reviewed a sample of those found to have epilepsy by the Primary Health Care Worker, as a quality assurance.

A rural community prevalence for epilepsy of 13.3/1,000 was found, which is similar to other African countries. A treatment gap of 93% confirmed clinical impressions. The vast majority of people with epilepsy in the district were not receiving treatment.

### **Intervention to Improve Treatment**

People found to have epilepsy were asked to fill out a questionnaire about their quality of life. In addition, interviews with people with epilepsy and their caregivers were conducted to correlate with the questionnaire results, and two focus group discussions were held.

### **Education**

Primary healthcare nurses and environmental health technicians attended a one day workshop, which included sessions related to background knowledge, diagnosis, management of epilepsy, psychosocial issues and attitudes. Subsequently they were involved in public talks both in health centres and villages. The technicians trained village health workers (lay members in the community with an interest in health and health care) and supplied them with literature in the local language. The nurses and the district health education officer gave presentations in schools. In addition, a seminar was held with participation of one teacher from each school in the area, to enable this teacher to act as an epilepsy resource person for the school and for parents. Each of

these teachers was asked to organise at least one activity related to epilepsy in the school (i.e. produce a play, speak at a public function, organise a competition, etc.).

### **Quality of Life (QOL) Survey**

There were fewer responses for this study, as many people were not attending clinics due to two factors, which were the unavailability of medicines at most of the clinics and in some areas people had migrated due to the land reform program.

- PHC played a huge role because there were no doctors.
- Patients did not go to Hwedza Hospital or Harare where they were referred for further treatment because of cost
- Medication was not available at clinics
- It was not clear if the following had improved for patients:
  - Seizure frequency or severity
  - Side effects
  - Functional impact – improved work or not
  - Carer improvement as a result of treatment
  - Contribution to household and community
  - Relationships
  - Overall health
  - Future plans and ambitions
  - Standard of living

### **Results**

- Number of people randomly sampled: 6,274
- Number screened as possibly having epilepsy: 636
- Number screened as positive for epilepsy: 84
- Prevalence: 84/6274 (13.4/1000) or 1.34%
- Attendance before intervention: 83
- Attendance after intervention (2003): 198
- Previous treatment gap: 93.1%
- Treatment gap after intervention: 83.6%
- Increase in persons with epilepsy being treated: 138.5%
- Estimated reduction of persons with epilepsy not treated: 10.2%

### **Conclusions**

- Training primary health care workers to diagnose epilepsy (generalised convulsive seizures) is effective and safe. In quality assurance visits by the principal investigator no patients were found to have been treated inappropriately. Recommendations were made to the National Drug and Therapeutic Committee as well as the Ministry of Health and Child Welfare to adopt a national policy of primary health care worker training to diagnose and treat forms of epilepsy.
- It was proven to be possible to apply training and public education interventions in the most unfavourable environments (shortages of health workers for example).
- Training and awareness increase attendance for treatment

## **Section 6      Demonstration Project in China**

### **Introduction and Situation Analysis**

The People's Republic of China is situated to the east of the Asian continent. It covers 9,600,000 km<sup>2</sup> and is divided into 23 provinces, 5 autonomous regions and 4 municipalities. These divisions contain 335 districts, 2858 counties, 48,000 towns and 822,000 villages. According to the national records, in 1998 China had a population of 1.25 billion people of 56 different ethnic groups. The urban population was 379 million (30.4%) and the rural population was 869 million (69.6%). The Chinese gross national product (GNP) was ¥7955 billion (US\$980.2 billion with GNP/capita being US\$780) in 1999; urban resident income was ¥5425 whilst rural resident net income was ¥2160 in 1998. Since the adoption of policies leading to economic reform and opening to the outside world, the Chinese primary health-care system (the three-tier rural medical care system: county " town " village) has further developed its disease control activities and health campaigns. The system now provides comprehensive and sustainable health care to rural and semi-rural populations and covers the great majority of the population. There are two million professional health workers (including western and Chinese physicians), averaging 1.6 per 1000 population. The medical care system is currently undergoing reforms with the result that health service coverage is expanding. This is part of the Chinese government's efforts to attain the strategic goal of health for all. One of the greatest problems facing people with epilepsy is the stigma placed upon them by the community. Studies in China suggest that people with epilepsy are generally withdrawn from society; they feel isolated and are either overprotected or neglected.

### **Overall aims**

1. To generate procedures that would improve the identification and management of people with convulsive forms of epilepsy, in rural and semi-rural areas of the country, within the existing primary health care system and with community participation.
2. To develop a model of epilepsy treatment at primary health level that could be applied nation-wide.

### **Specific aims**

1. To assess current management practices (identification, treatment and follow-up) of patients with convulsive forms of epilepsy in rural and semi-rural areas of the country.
2. To estimate: a) the prevalence of active forms of convulsive epilepsy, b) the scale of the treatment gap via an active case finding methodology, and c) changes the project may bring to these figures in the study area.
3. To ascertain the knowledge, attitudes and practice of epilepsy amongst health practitioners at primary health level prior to the study and after they have undergone training for epilepsy.
4. To develop technical norms for the identification, education, treatment and follow-up of patients with epilepsy at primary health care level.
5. To carry out a feasibility study, by primary health care doctors, of the treatment of convulsive forms of epilepsy using phenobarbital.
6. To develop a programme for continuous professional education on epilepsy for primary health.
7. To promote public awareness about epilepsy via an educational programme aimed at the community.
8. To develop local advocacy and support groups for people with epilepsy.



9. To reduce the economic and social burden of epilepsy in the study areas.

### **Methodology**

This demonstration project was composed of three parts:

1. Epidemiological estimation: to provide a realistic estimation of the prevalence of untreated active epilepsy in the study areas.
2. Service Delivery (intervention study): to cover the issues of diagnosis, phenobarbital treatment, follow up referral networks.
3. Educational, social and community intervention: to cover the educational and social aspects of the project.

### **Epidemiological Estimation and Results**

A door-to-door survey was carried out in 5 representative counties each with a population of about 10,000 people (total population: 50,000). A screening questionnaire was designed to identify patients with convulsive seizures. The questionnaire was validated at the Beijing Neurological Institute for specificity and sensitivity. The questionnaire was based on the WHO screening questionnaire previously used in China and on the ICBERG screening instrument. Adjustments to the questionnaire were made accordingly. All participants were trained to use the validated screening questionnaire and mastered the standard before survey. The survey was repeated using a similar methodology and instruments at the end of a four-year period to ascertain whether there had been a measurable change in the treatment gap in the areas surveyed.

### **Service Delivery (Intervention Study) and results**

Patients who qualified for entry into the study received treatment with phenobarbital according to the technical norms set out. The town hospital physicians completed a study entry form at this point. Demographic details and a pragmatic retrospective estimation of the numbers of seizures, particularly convulsions, which the patient had experienced in the previous, week, month and year, were recorded. A record of the current occupation status of the patient (work and school) was made. If the patient was employed, or attended school, an estimation of absence from work or school due to epilepsy was made and recorded. The senior primary health care physicians and village doctor explained to the patient the importance of regular compliance with medication and how it should be used. The patient was informed about common side-effects of the medication and advised to report to the doctor any untoward effect that they might experience once treatment had started. The patient was provided with contact information for the primary health care team and also instructed on the importance of follow up visits. Patients included in the study were invited to attend the town hospital or village clinic every two weeks for the first two months, and monthly thereafter, for dose adjustments, side-effects assessment, compliance checking and to receive further supply of the medication. The doctor filled out a follow-up form for each visit. Number of seizure, side effects and effects of treatment were recorded. If the patient reported the presence of side effects, the senior primary health care physicians dealt with these according to instructions in the technical norms. In case of doubts, or if the side-effects were severe or persistent, the patient was referred to the local neurologist. Compliance was assessed at every follow-up appointment according to given instructions. The patient or his/her parents recorded the seizures, the medication taken, any effects of the treatment and other issues. Those patients working or at school were questioned about their attendance record from the previous visit and any changes of occupational status were recorded. The village doctor could at any time request a review by the senior physician if severe side-effects developed, or in the case of clinical

uncertainty, or if the patient's seizure control proved to be difficult. The patient was reviewed at least once every three months by the local neurologist in charge of the case. Patients were withdrawn from the study if one or more of the following situation arose:

1. The treatment was found not to be effective by the supervising doctor.
2. The patient experiences an important deterioration in seizure control (i.e. an increase of 50% or more of seizures or status epilepticus).
3. Patient or guardian decided against continuing treatment.
4. The patient was found to be non-compliant with the treatment in 3 consecutive opportunities.
5. The patient failed to attend 3 follow-up appointments.
6. The patient was found to have a progressive neurological disorder.
7. The patient developed a heart, liver or kidney condition.
8. The patient developed severe side-effects to phenobarbital, confirmed by the supervising doctor. If a patient withdrew from the study, a termination form was filled out recording the reasons for the drop out. The patient received alternative or further treatment or was referred to another level of care, according to clinical needs.

### **Educational, Social and Community Intervention and Results**

All physicians and a number of village doctors in each of the study areas received basic epilepsy training. This was provided by the team of the Beijing Neurosurgical Institute and by the local neurologists who collaborated in the study. The training module covered the following aspects:

- \* Epidemiology of epilepsy
- \* Public health aspects of epilepsy
- \* Causes of epilepsy \* Differential diagnosis of epilepsy
- \* Diagnosis of epilepsy and particularly of generalised tonic clonic convulsions
- \* Drug treatment of epilepsy
- \* Management of epilepsy
- \* Nature of the study and how to fill in the study forms

Each of the doctors attending this project in training received a work plan. Prior to the start of training all doctors completed a questionnaire to ascertain their knowledge, attitudes and practice (KAP) in relation to epilepsy. To assess the effectiveness of the training module, all participants were asked to complete the same questionnaire between 3 and 6 months later. A Chinese version of the KAP questionnaire, developed by the Pan American Health Organisation (PAHO), was used. An educational programme about epilepsy was introduced throughout the study areas via a number of media channels and aimed to show the general community that epilepsy is a treatable disorder. The programme provided information about:

- \* The nature of epilepsy: its characteristics, cause and prognosis.
- \* The nature of treatment, its objectives, the use of medication, the importance of compliance, the potential side effects of medication and the duration of treatment.
- \* General health measures and emergency treatment of seizures. The content of the programme was prepared by the team at the Beijing Neurological Institute and by the Beijing Epilepsy Association. Information sheets were handed to the patients and their families. A number of local physicians and neurologists lectured the patients and their families on a regular basis. Lectures and group discussions for patients and their families were also arranged during this time, and community leaders and local teachers were presented with information about epilepsy, its causes and its treatment. Patients were encouraged by the media and by community leaders to come for free diagnostic assessment and for management when appropriate. In addition, an educational

programme, aimed at decreasing social stigma in areas of social relations, employment, leisure activities, schooling, etc., was developed. This was aimed at local primary and secondary school teachers because they exercise an important role in their communities. The aim of this programme was to address attitudes regarding aetiology, shame and to explain that epilepsy is not infectious. A revised version of the instrument used in a survey of public awareness, understanding and attitudes toward epilepsy in Henan province was completed by the teachers before and after the educational programme to assess changes. Other activities carried out in the communities included:

- \* Informing people about epilepsy through public-address systems
- \* Disseminating materials on epilepsy
- \* Putting up posters
- \* Developing local Advocacy/Support Groups.

A second epidemiological survey was carried out between September and December 2004 after the above interventional and educational studies had been completed. This showed a minimum lifetime prevalence rate of 6.2/1,000 which is slightly lower than that of the previous survey. The prevalence of active epilepsy was 4.5/1000, similar to that found previously. In this survey half of the patients with active epilepsy had received anti-epileptic treatment in the previous week.

### **Organizational Context and Management Structure**

Dr L Prilipko and Hanneke M de Boer were the Facilitators of this project on behalf of the Global Campaign Secretariat and also acted as supervisors/monitors of the project. Prof JW Sander was the Scientific Project Leader. The Department of Disease Control and the Department of International Co-operation of the Ministry of Health, Peoples Republic of China were responsible for the Demonstration Project and delegated the tasks of ensuring concerted action to the Beijing Neurosurgical Institute. An Executive Committee was established at the Beijing Neurosurgical Institute. The members included each local co-ordinator and leader of the Public Health Bureaus. An advisory panel was also constituted and consisted of a representative of WHO, a representative of the Global Campaign Against Epilepsy, a representative of the local WHO office, members of the Executive Committee, the local co-ordinators, a member appointed by the local Public Health Bureau from each of the counties involved, a representative of the Neurological Society of China, a representative of the Beijing Epilepsy Association and representatives from the Ministry of Health.

### **Sustainability**

This Demonstration Project was successful in implementing treatment and management of convulsive forms of epilepsy in rural areas of China. Physicians with basic training have been shown to be able to treat people with epilepsy using Phenobarbital as the first option. This cost effective approach can make a difference to the treatment gap in epilepsy; which was reduced by about 13% between 2001 and 2004. Phenobarbital treatment as a first option for epilepsy has now been extended to 80 counties in 15 provinces in China. By the end of August 2008, over 35,000 people with epilepsy had been treated according to this protocol. It is scheduled to become part of a national epilepsy programme in the next few years.

## Section 7 Demonstration Project in Brazil

### Introduction and Situation Analysis

Brazil is a country of continental dimensions (8,511,965 km<sup>2</sup>) located in South America. It is divided into 32 federal units. According to the census of 2000 it has a population of 170 million inhabitants. It has been a Republic since 1889 with a government consisting of three powers: Executive, Legislative and Judiciary. It has an elected President, National Congress (Congress and Senate), and a Supreme Court. The gross internal product (GIP) of the country (2000) averaged R\$6,559.94 (US\$2,630.00) per capita, but with striking regional differences. The unemployment rate has been estimated to be around 6% in metropolitan areas (2000). The illiteracy rate decreased from 25.5% in 1980 to 20% in 1991. In southern and south-eastern regions the illiteracy rate of those younger than 24 years is 4% (1991). Brazil has a well-structured federal constitution which states that health is the right of every citizen and the duty of the State. This became official state policy by a law passed on September 19th 1990 thereby creating the Unified Health System (Sistema Único de Saúde [SUS]). It is estimated that SUS provides health care coverage to 77% of the population in Latin America and the Caribbean. Few epidemiological studies have been carried out in Brazil. Marino et al. (1986) found a prevalence of epilepsies. According to data accessed by the Ministry of Health, epilepsies rank 30th place among the principal causes for hospitalization. Possibly the majority of these is comprised of patients with status epilepticus or with frequent seizures. Parasitic diseases are risk factors which may explain the high incidence of epilepsy in developing countries, including Brazil. Main causes of epilepsy in the country are: \* Neurocysticercosis is the most prevalent of these parasites, and it is endemic in the south-eastern, south, and central-western regions. It is the most often diagnosed risk factor associated with epilepsy in adults in these areas. \* Perinatal brain damage is another risk factor to explain the high incidence of epilepsy. This is possibly true in regions with inadequate prenatal care. \* High incidence of motor vehicle accidents leading to traumatic brain injury is also an important risk factor of epilepsy. The basic strategy for the prevention of epilepsy, in a country like Brazil, should include prenatal care, safe delivery, control of infectious and parasitic diseases, and reduction of brain injury due to traumatic brain injury and stroke. In addition to increased risk of morbidity and mortality associated with epilepsy, patients face stigma placed upon them by the community. Stigmatization prevents patients from disclosing their condition and, at times, from seeking treatment. This clearly has an impact on employment, education and, ultimately, on patients' quality of life and their integration in society. Treatment with antiepileptic medication can render up to 70-80% of patients seizure-free. The most frequently prescribed antiepileptic drugs (AEDs) in the country are: carbamazepine (29%), clonazepam (22%), phenobarbital (17%), phenytoin (11%), Valproate (8%).

### Objectives

This project aims at testing the feasibility of diagnosing and treating epilepsy at primary care level with rational use of the first line antiepileptic drugs (phenobarbital, phenytoin, carbamazepine, and valproic acid). The long-term prospect is to integrate epilepsy management into the existing primary health delivery system in a sustainable manner. If this project is shown to be effective it will be recommended for implementation nationwide.

## **Overall aims**

\* To generate procedures that will improve the identification and management of people with epilepsy in urban area within the existing primary health care system and with community participation.

\* To develop a model of epilepsy treatment at primary health level that can be applied nationwide.

## **Specific aims**

1. To assess current management practices (identification, treatment and follow-up) of patients with epilepsy in urban areas of the country.
2. To estimate: a) prevalence of active forms of epilepsy, b) the scale of the treatment gap via an active case finding methodology and, c) changes that this project may bring to these figures in the study area.
3. To ascertain the etiology and risk factors in association with epilepsy in the community.
4. To reduce and eradicate preventable causes of epilepsy in the community.
5. To ascertain the knowledge, attitudes and practice of epilepsy amongst health practitioners at primary health level prior to the study and after they have undergone training for epilepsy.
6. To develop technical norms for identification, education, treatment and follow-up of patients with epilepsy at primary health care level.
7. To carry out a feasibility study of the treatment of forms of epilepsy using first line antiepileptic drugs by primary health care physicians.
8. To develop strategies for the implementation of a cost-effective surgical program for the treatment of epilepsy.
9. To develop a program for continuous professional education on epilepsy for primary health workers.
10. To promote public awareness about epilepsy via an educational program aimed at the community.
11. To promote continuing education for primary and secondary level school teachers and diffusion of information on epilepsy.
12. To develop a program to de-stigmatize epilepsy and improve its social acceptance.
13. To develop local advocacy and support groups for people with epilepsy.
14. To reduce the economic and social burden of epilepsy in the study. areas.

## **Methodology**

This demonstration project is composed of three parts:

### **1. Epidemiological estimation.**

This provides a realistic estimation of the prevalence of epilepsy and untreated active epilepsy in the study area. The epidemiological exercise aimed to estimate the prevalence of active epilepsy and the treatment gap. A door-to-door survey was carried out in the study area using the screening questionnaire based on a local modified Portuguese version of ICBERG (screening instrument). The survey was repeated using a similar methodology and instruments at the end of the four-year period to ascertain if there had been a measurable change in the treatment gap in the areas surveyed.

### **2. Service Delivery (Intervention Study).**

This covered the issues of diagnosis, AED treatment, follow-up and referral networks. The target population consisted of patients with epilepsy, treated or untreated, who lived in the study area. A variety of case-finding methods was used. Identification of patients was initially carried out by health assistants, whilst local neurologists were responsible for checking the patients who had been selected and referred for complementary examinations. Identified patients were invited to participate in this study. Patients who did not wish to enrol in this study did receive medical treatment. Patients with confirmed diagnosis of epilepsy who wished to participate in this study were enrolled in the study protocol. Health assistants at the primary health centres were responsible for explaining the nature of this study, obtaining a written consent form and complete a study entry form. Physicians at the primary health centre were responsible for prescribing medication, and filling in the medical report forms. At the end of 12 months treatment, one objective and two subjective assessments were carried out to determine the effectiveness of the treatment. In order to ensure the quality of the project, a framework for monitoring the project was devised. The members of the Executive Committee monitored the project's progress and checked the study area every 3 months. Annual reports on the progress of the project were generated.

### **3. Education, Social and Community Intervention.**

This covered the educational and social aspects of the project. The project lasted four years. During the first year, the following activities were carried out:

- \* Preparation of training modules
- \* Design of instruments, including the screening questionnaire
- \* Drafting training material and work menu
- \* Validation of screening questionnaire
- \* Training of trainers
- \* Training of family physicians
- \* Door to door survey
- \* End of first year assessment

All physicians and nurses received basic epilepsy training. The training modules were standardized and covered the following aspects:

- \* Epidemiology and public health aspects of epilepsy
- \* Classification of seizures and epileptic syndromes
- \* Causes of epilepsy
- \* Differential diagnosis of epilepsy
- \* Drug treatment of epilepsy
- \* Management of epilepsy
- \* Febrile convulsion and benign childhood epilepsy syndromes
- \* Nature of the study and how to fill in the study forms

Each primary health care team also received a work plan. All physicians completed a questionnaire to ascertain their knowledge, attitudes and practice (KAP) in relation to epilepsy prior to the first training session. To assess the effectiveness of the training module, all participants completed the same questionnaire 3 to 6 months later. An educational programme was directed at patients and their families.

It is aimed at informing them about:

- \* The nature of epilepsy, its characteristics, cause and prognosis
- \* The nature of treatment, its objectives, the use of drugs, the importance of compliance, the potential side effects of drugs, and the duration of treatment
- \* General health measures and emergency treatment of seizures

The issue of stigma in epilepsy and layman perception and prejudice against patients with epilepsy was explored in different segments of society. An educational program aimed at decreasing the level of social stigma in areas of social relations, employment, leisure activities, schooling, etc, was developed. This was aimed at local primary and secondary school teachers because they exercise an important role in their communities. The aim of this program was to address attitudes regarding aetiology, shame and the lack of infectiousness of epilepsy. A questionnaire on public perception of epilepsy was applied to the teachers before and after the educational program, as well to students, to assess changes. Assistance was given to create advocacy/support groups composed of local laymen and health professionals.

### **Organizational Context and Management Structure**

This demonstration project was based on the guidelines of the Global Campaign Against Epilepsy, which was launched in 1997. Professors Li Li Min and Ley Sander were the coordinators of the project. The Department of Neurology was responsible for the work involved in the Demonstration Project. The Project was carried out in the District of Baro Geraldo in Campinas; and Districts of Santo Antonio and Jaguar in So Jos do Rio Preto. The main setting of this project was based at the local primary health centres of these three Districts under Municipal Health Departments and their referral tertiary centres. Responsibility for local activities rested with the local personnel. The Project was co-ordinated by Hanneke M de Boer (ILAE/IBE) and Dr Leonid Prilipko on behalf of WHO.

## **Section 8      Demonstration Project in Senegal**

### **Introduction and Situation Analysis**

Senegal is a West-African country that covers a territory of 69,700 km<sup>2</sup> and has a population of 10 million. Of the population 45% are less than 15 years of age, 54% are female and 55% live in rural areas. The health system is structured as a pyramid, constituted from the base to the top by: health posts (villages and rural community), health centres (cities), regional hospitals and (2) university hospitals. There is a wide disparity of medical personnel: 90% of specialised doctors are concentrated in Dakar. More than 50% of the countries medical doctors, pharmacies, nurses and midwives are based in the Dakar region. The mean national prevalence rate of epilepsy in Senegal is estimated to be 8.3%. Different epidemiological research projects have emphasised the important differences from one region to another. In the suburban area Pikine, characterised by promiscuity and problems of hygiene and water supply, the prevalence raises to 12%. The Pikine Health District is a poor suburb of Dakar with a population of 480,000 of whom 57% are younger than 20 years of age. Pikine is a conglomerate of traditional villages, resettlement houses and squatters homes. Some limited primary maternal and infant health plans exist.

#### **Overall aims**

- To decrease the treatment gap
- to develop a model of epilepsy care in terms of identification, treatment, prevention, education, training and research

#### **Specific aims**

To evaluate knowledge, attitude and practice about epilepsy

- to assess local cultural beliefs and health seeking strategies
- to develop epilepsy training modules
- to strengthen health personnel capacity to detect and manage epilepsy
- to ameliorate access to and availability of antiepileptic drugs
- to assess current management practices and to promote their improvement
- to improve the prevention of epilepsy
- to ameliorate epilepsy knowledge and required attitudes of teachers
- to ascertain education on epilepsy to patients and their families
- to promote general awareness about epilepsy and to fight the stigma surrounding the condition
- to set up local support groups
- to reduce the social, economic and professional burden faced by people with epilepsy

#### **Methodology**

##### **Epidemiological survey**

A multi-disciplinary and multi-dimensional approach was used to establish services for epilepsy and to ensure that these would be integrated into the national health service. The strategy consisted of:

- preparation phase
- national intervention



- pilot intervention studies

This Demonstration Project consisted of a survey of people with epilepsy in the project site. This was followed by training and educational interventions. Finally a second survey to evaluate their expected impacts on awareness, treatment gap, knowledge and services was performed.

### **Public education**

The interventions consisted of the distribution of training materials for health professionals, leaflets specifically for people with epilepsy and information for the general public .A television documentary and advertising message were developed with the participation of the First lady, the Ministry of Health, the National Wrestling Champion and a Music Celebrity and, finally, weekly broadcasting on epilepsy. A Drug Bank providing Phenobarbital was set up.

Training Seminars were organized for:

- Primary school teachers
- Students from 5 primary and 2 secondary schools
- Doctors and health personnel from public and private enterprises
- Later, weekly specialised consultations for epilepsy were organized.

### **Conclusions**

The Demonstration Project in Pikine revealed that the public health methodology applied was effective, despite the difficulties related to the context, and could be extended to the rest of Senegal. The methodology could also be proposed as a model that could be suitably adapted for use by other countries of the Region, taking into account local specificity.

### **Organizational Context and Management Structure**

The Ministry of Health had been instructed by the Prime Minister of the country to initiate a Demonstration Project. A co-ordination team was set up consisting of the Director of Health of the Ministry of Health and the Executive Board of the Senegalese League Against Epilepsy (SLAE). Training, research and care activities were co-ordinated by the SLAE Research and Training Commission. Education, information and social activities were managed by the SLAE Socio-Educative Commission. The project was supported by the Service of Health Education of the Ministries of Health and of Social Affairs, Woman and Child. The Project was facilitated and monitored on behalf of the Global Campaign Secretariat by Prof Ley Sander, the scientific project leader of the Campaign, and by Prof Harry Meinardi. The project was facilitated and monitored by members of the Campaign Secretariat (Dr Leonid Prilipko and Hanneke M de Boer).

# Appendices

## ***Appendix 1 Protocol for Hwedza District Demonstration Project***

### Contents

1. Introduction and Situational Analysis
2. Management Structure
3. Organisational Context
4. Definitions
5. Aims
6. Methodology:
  - Duration of the Project
  - Epidemiological Survey
  - Treatment Intervention
  - Education
7. Outcome Measures
9. Research tools
  - Prevalence Survey Questionnaire
  - Quality of Life Questionnaire
  - Health Services Survey
  - KAP for Health Care Workers Questionnaire
  - Public Perception towards Epilepsy Questionnaire
  - Budget
  - Logical Framework Analysis

### ***1. INTRODUCTION AND SITUATIONAL ANALYSIS***

#### **A. GENERAL INFORMATION**

Zimbabwe is a landlocked country situated in Southern Africa. It has a population of around 12 million people with a growth rate of 2.2%. Just over 50% of the population are in the economically active age group of 15-64 years old, while 40% are under 15 years of age. The size of the country itself is 391,000 sq. km which means that there are approximately 2 people/sq. km. 35% of the total population live in urban areas {World Bank 2000 ID: 35}.

Approximately 98% of the population is African (Shona 71%, Ndebele 16%, other 11%), while 0.5% are whites, mixed races and Asians make-up the final 1%. Despite this, English is the official language, although both Shona, Sindebele (the language of the Ndebele) and other African languages are widely spoken {CIA 2001 ID: 171}. Literacy for adult men is 92%, while that for women is around 83% {World Bank 2000 ID: 35}.

Zimbabwe's Gross National Product (GNP) is just over US \$6 billion and is ranked 102<sup>nd</sup> in the world. GNP/capita is around US \$400. However, according to estimates in the early 1990s 64.2% of the population lived below a poverty line calculated as earning less than US

\$2/day{World Bank 2000 ID: 35}. Despite large mineral and agricultural resources, the country's economy has suffered in recent years from political instability, involvement in the war in the Democratic Republic of Congo, the AIDS pandemic (30% of ante-natal clinic attenders have been shown to be HIV-positive in both rural and urban surveys) and from the outside economic pressures of multilateral organisations, such as the World Bank and International Monetary Fund. Inflation, for example, rose from an annual rate of 32% in 1998 to 59% in 1999.

Government expenditure on health is equal to 3.1% of Gross Domestic Product or US \$175 million. (GDP stood at US \$5.7 billion in 1999, of which US \$900 million arose from government expenditure). In terms of public health, 77% of the population have access to safe water and 66% have access to adequate sanitation. Life expectancy at birth stands at 49 years for men and 52 years for women, while mortality of the under-5s is 125/1,000{World Bank 2000 ID: 35}.

The present prevalence of epilepsy in Zimbabwe is unknown, in 1970 Levy et al reported a prevalence rate of 7.4/1000 based on a community-based survey of 17 000 rural inhabitants (African Journal Medical Science 1970), which is consistent with population-based studies in Nigeria and Ghana, but not with very high figures reported from Tanzania and Liberia. The figures are of a similar order of magnitude as European and North American results:

COUNTRY	Author	PREVALENCE Rate/1.000	COMMENTS
South Africa	Bird et al, 1962	3.7	survey in 200 Bantu mine workers
Rhodesia	Levy, 1970	7.4	population-based study on 17 000 rural inhabitants
Ghana	Haddock, 1973	4.0	population based study
Uganda	Orley, 1970	2.1-3.7	community based study on 13 174 rural population
Tanzania	Jilek-aall et al, 1979	20.0	community-based study in isolated population of 10 000
Nigeria	Dada, 1970	3.1	population based in Lagos involving 14 000 people
	Osuntokun et al, 1987	5.3	community-based survey of 20000 rural people
Ethiopia	Tekle-Haimanot et al, 1990	5.0-8.0	community-based involving 3200 people
	Giel, 1970	5.3	community-based study of 60 820 rural people
Liberia	Van der Waals, 1983	28.0	community-based study in an isolated rural clan of 4 436

USA	Hauser & Kurland, 1975	4.5-6.5	based on review of medical records
England	Brewis et al, 1976	5.5-6.0	based on review of medical records in an English city
Colombia	Gomez et al, 1978	19.5	population-based study in Bogota city on 8 658
China	Li et al, 1985	4.4	population-based study on 63 195

## **B EPILEPSY CARE IN ZIMBABWE**

### **B1 GOVERNMENT STRUCTURES**

In a rural area a person with epilepsy will first attend a rural health centre where a primary health care worker (PHCW) such as a primary health care nurse (PHCN) would attend him. Until 2000 the policy was that cases of suspected epilepsy would be referred to the secondary level centre, the district, general or mission hospital for diagnosis and initiation of therapy by a medical officer, with subsequent follow-up at the rural health centre. Difficult cases would be referred for specialist opinion at a tertiary hospital in a provincial centre or a quaternary (central hospital) referral centre. Since the introduction of the EDLIZ 2000 (the national formulary and management guidelines = Essential Drug List of Zimbabwe) provision is made for the diagnosis and initiation of therapy for convulsive epilepsy by PHCNs trained in epilepsy management. Follow-up at home includes recording the person with epilepsy (PWE) in a chronic diseases register and contacting defaulters at home. This task is performed by environmental health technicians attached to rural health centres. PWE attend their local clinic monthly for drug re-supplies, which are free but sometimes unavailable. Psychiatric nurses visit rural health centres once a month and may advise PHCNs about management, as epilepsy falls within their area of training and expertise, likewise epilepsy is recorded under mental health statistics nationally. Secondary level facilities are manned by government medical officers and district medical officers. These are generalist medical doctors who have completed at least two years post graduation in central hospitals and treat the entire range of clinical presentations. At a tertiary level, a specialist physician (specialist in internal medicine) or paediatrician sees PWE referred to him, but might refer patients to a central hospital for further investigations (CT scan, MRI scan, EEG) and a neurologist or neurosurgeon's opinion. The latter two are only available in Harare, where a specialised epilepsy clinic caters for PWE with intractable epilepsy or special epilepsy syndromes,

### **B2 NON-GOVERNMENTAL ORGANISATIONS**

The Epilepsy Support Foundation of Zimbabwe is a lay organisation composed of PWE and functions to improve the well-being of its members. It is headquartered in Harare and has thriving sections in Bulawayo, Mutare, Masvingo and Kadoma. Its activities are primarily educational, both of the public and its members and their families. Other spheres of activity include the formation of support groups with income-generating projects, advocacy with employers and schools, co-operation in research projects and international liaison.

Mission hospitals play an important role in rural health care in Zimbabwe, and have been integrated into the government health structures to provide primary care , often acting as district hospitals and receiving support from both the parent church denomination and the Ministry of Health.

### B3 THE ZIMBABWE DEMONSTRATION PROJECT

The demonstration project came about through the formation of a Zimbabwe Campaign against Epilepsy committee which was initiated subsequent to the launch of the Global Campaign against Epilepsy at the International Epilepsy Conference in Dublin in September 1997. Members of the Zimbabwe committee include representatives from the Epilepsy Support Foundation (the lay organisation to support people with epilepsy in Zimbabwe), the Zimbabwe League against Epilepsy (the International League against Epilepsy chapter in Zimbabwe), the Ministry of Health and Child Welfare, the Zimbabwe office of the World Health Organisation and the Department of Psychiatry of the University of Zimbabwe Medical School, a collaborating centre for the World Health Organisation .

In 1998 Zimbabwe was selected to host a demonstration project, and work began to prepare project proposals for a number of different interventions in different areas. With the presentation of the protocol for a Chinese demonstration project, and with the participation of the Scientific Advisor of the Global Campaign a decision was made to focus the demonstration project in one area and to use similar protocols for all the demonstration projects, in order to be able to compare findings.

#### 2. MANAGEMENT STRUCTURE

The project will be managed by the Zimbabwe Committee of the Global Campaign against Epilepsy, described above. The principal investigators ( Drs J Mielke and D Ball ) will form a core sub-committee, onto which the District Nursing Officer and the District Medical Officer of Hwedza district will be invited. An administrative assistant will be employed to implement and convey decisions. The investigators will hire and train individuals as surveyors and for other tasks in the district.

#### 3. ORGANISATIONAL CONTEXT

The next step was to select a suitable study area, which needed to satisfy the following criteria:

1. Accessibility – it will have to be possible for investigators to reach the area from Harare, on a frequent basis. Both distance and terrain have to be considered.
2. Size – a study population of around 100 000 was envisaged
3. Health facilities – existing health centres and their current functionality are an important component of the project

4. Health staff – government health care managers as well as primary health care staff who are willing and able to be involved are necessary for the implementation of the program

#### HWEDZA District

This administrative district is approximately 140 km south-east of Harare. It is reached by a good quality tar road and has an area of 2560 km<sup>2</sup> with a population of 90 350. It consists mainly of communal farming areas (where subsistence farming in family groups is practised ) with a number of commercial farms also present. The health infrastructure includes a mission hospital, Mount St Mary's Mission Hospital, which is also designated as the (government) district hospital, one rural hospital , 4 government rural health centres and 5 rural district council clinics. Apart from the mission hospital staff there is one medical officer. The hospital matron ,the district nursing officer , 5 state registered nurses and 11 state certified nurses make up the nursing staff. There are also 8 environmental health technicians supervised by a district environmental health officer.

District figures for 2000 include 489 patient contacts for epilepsy, with 4 new patients . Since patients are reviewed monthly, this would indicate a prevalence of 0.45 / 1000 and an incidence of 4.4/100000, if reporting and compliance were 100 %. Comparing with figures in table 1 above it is likely that a significant treatment gap ( of around 90%) therefore exists.

#### 4. DEFINITIONS

For the purpose of this project the following definitions will be used:

**Active Epilepsy:** Someone who has suffered 2 or more unprovoked convulsive seizures in the 12 months immediately preceding identification by project personnel.

**Unprovoked Seizure:** Epileptic seizures not associated with a clear precipitant or triggering factor (such as drugs, fever, acute head injury, acute cerebro-vascular accident, acute metabolic imbalance).

**Convulsive Epilepsy:** Primary or secondarily generalised tonic clonic convulsions, with or without other seizure types.

**Untreated Epilepsy:** Any patient with active epilepsy who has not received regular antiepileptic drug treatment in the week preceding identification by project personnel.

**Epilepsy in remission on treatment:** a prevalent case of epilepsy without seizure for five years or more and taking AED at the time of ascertainment.

**Epilepsy in remission off treatment: a prevalent case of epilepsy without seizures for five years and not taking AED at the time of ascertainment**

**History of epilepsy:** a case who had more than two seizures during life time but is off treatment and without seizures for more than five years.

**Appropriate Medical Treatment:** Appropriate treatment of active epilepsy would include diagnosis and treatment of underlying causes, as well as treatment of recurrent seizures according to international standards, using antiepileptic drugs and surgery where feasible.

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

## 5. OBJECTIVE AND AIMS

The overall objective of the project is to improve the quality of life of people with epilepsy in rural Zimbabwe. In order to achieve this objective, it aims to:

1. Discern the prevalence of epilepsy and its treatment gap in a rural area
2. Discern influence of epilepsy on the quality of life of people with epilepsy in a rural area.
3. Positively influence the physical quality of life of these people with epilepsy through a pharmaco-economic intervention (ensuring availability and accessibility of medical care and medications).
4. Positively influence the social quality of life of these people with epilepsy through a psychosocial intervention (a health education campaign for health staff, patients and their families, and the public).

## 6. METHODOLOGY

The Global Campaign's demonstration projects are composed of three parts:

1. Epidemiological Survey
2. Intervention to Improve Treatment
3. Education

The two interventions (pharmaco-economic and psychosocial) will be applied in the following way:

- Divide study area into four (A, B, C and D) - the division will be according to geographical borders, and the health centres' areas of influence. The district has 9 rural health centres, so that 2 centres will constitute a sub-district for the purposes of the study.
- A single intervention will initially take place in two of the divisions. After six months each division will receive the intervention it did not previously receive, while the other two divisions will receive both interventions simultaneously. (Cross-contamination, especially as regards public education campaigns, is inevitable (rural people in Zimbabwe are very mobile

although their permanent dwelling, the rural home or “kamusha”, tends to remain as one locality). However, health system interventions such as improving drug delivery and primary health care nurse education can be focused in a particular sub-district).

### ***Duration and Timeframe of the Project***

The project is initially intended to last approximately 18 months and if successful it may be pursued further. It will progress in the following manner:

- 1<sup>st</sup> Quarter: Initial survey for case-finding, health services and attitudes towards people with epilepsy.
- 2<sup>nd</sup> and 3<sup>rd</sup> Quarter: Interventions in “A” (pharmaco-economic) and “B” (education) for six months.
- End of 3<sup>rd</sup> Quarter: All areas are surveyed again after six months.
- 4<sup>th</sup> and 5<sup>th</sup> Quarter: Interventions in “A” and “B” swap around and “C” and “D” receive both interventions simultaneously.
- End of 5<sup>th</sup> Quarter: All are surveyed again at one year.

## **6.1 Epidemiological Survey**

All areas (A, B, C and D) are surveyed initially. For this local senior high school children may be recruited, and trained in the application of the questionnaires in Appendix 1. A community-based door-to-door survey sampling the entire district is envisaged. A cluster sampling approach may be most suitable, taking into account the spread of the local population into small villages. Sampling needs to take into account the lack of identification of dwelling places (no street or stand numbers) and the lack of reliable demographic data. The questionnaire for the prevalence survey is being based on that used in demonstration project for China, as included in Appendix 1.

A questionnaire for people found to have epilepsy will be also used to discern their quality of life as a result of their epilepsy. This is based on Appendix 2 (which is taken from the Outcome Measures devised by the ILAE)

## **6.2 Treatment Intervention**

### **6.2.1 The health services in each area are surveyed**

This survey is still in development will take place alongside the epidemiological survey (it may consist of Appendix 3

### **6.2.2 “A” is subjected to a pharmaco-economic programme for six months**

The nature of the programme is under consideration at present, but will concentrate on ensuring the continuous availability of phenobarbitone at all rural health centres. This may include urgent supplies if indicated.

#### **6.2.2.1 Outline of pharmaco-economic intervention**



The central theme of long-term control of epilepsy remains drug therapy. Around three quarters of patients can be rendered seizure-free on appropriate monotherapy. However, this promise cannot be fulfilled unless the drugs are available and used rationally. This component of the demonstration project will examine issues related to the availability and use of antiepileptic drugs and perceptions of drug treatment by PWE.

It aims to:

- measure health service indications relevant to epilepsy
- evaluate the procurement and distribution of antiepileptic drugs so as to identify any limiting factors
- examine the impact of an assured supply of antiepileptic drugs (AED) on patient attendance at clinics and recorded seizure control
- assess patient perceptions of side-effects and other difficulties associated with taking AEDs

Methods

A factorial study design is to be used within a selected district, in Zimbabwe to investigate the effects of pharmaceutical and pharmacoeconomic intervention.

- a) Health service and patient care indicators relevant to epilepsy will be measured. A list of these is presented above in Appendix 3. Measurement will take place at baseline and at 6 months and 12 months.
- b) All clinics in the intervention area will be visited and provided with adequate stocks of AEDs if required. The District Hospital will also be provided with AEDs if needed. Monthly checks will be made to ensure adequate stocks remain available during the intervention period.
- c) Stock level assessments of AEDs at non-intervention clinics will be made on a 2 monthly basis. (Such visits will make these clinics want to be sure of having adequate stocks and it may therefore be a source of bias in the study).
- d) Attendance to clinics by PWE will be retrieved from all clinic registers on a monthly basis. Pre-intervention, all clinics will be advised/trained in keeping registers for PWE including recording the number of seizures in the past month. This data will also be collected to examine trends in reported seizure control.
- e) The Ministry of Health and Child Welfare will be approached to provide information on tenders for AEDs. In addition, district hospital pharmacy records will be examined for the same period (1999-2000) to determine when AEDs were ordered, when they were supplied and the stock carried. Clinic records will also be checked to determine past stock levels. The procurement and distribution chain will be examined for failures and the reasons for these investigated. The costs of treating PWE will be estimated.
- f) Focus group discussions will be held with PWE to investigate their perceptions of AEDs, side-effects and difficulties associated with the drugs and their supply. Willingness-to-pay for an assured supply of drugs and epilepsy treatment will be investigated.

g) PWE attending clinics at baseline and 12 months will be administered a questionnaire to assess quality of life (see Appendix 2).

### **6.2.3 “C” and “D” receive pharmaco-economic programme for six months**

As for 6.2.2.

### **6.2.4 “B” receives pharmaco-economic programme for six months**

As for 6.2.2.

### **6.2.5 Monitoring**

This intervention will be monitored by...

## **6.3 Education**

### **6.3.1 The attitudes of people towards epilepsy is surveyed**

Appendices 4 and 5 contain the questionnaires for health care workers’ knowledge, attitudes and practices (KAP) and the perception of the community towards epilepsy respectively.

### **6.3.2 “B” is subjected to a health education campaign for six months**

This campaign needs to include health professionals and the public:

- Primary health care nurses (PHCNs) and environmental health technicians (EHTs) attend a one-day training workshop, which includes sessions relating to background knowledge, diagnosis, differential diagnosis, management, psychosocial issues and attitudes.
- PHCNs and EHTs are involved in public talks both at health centres and in villages. EHTs train village health workers (lay members of the community with a health interest) and supply them with local language literature. PHCNs or the district health education officer give talks at schools.
- A seminar for one teacher from each school in the area is held, to enable this teacher to be the epilepsy resource person for the school and its parent body. He is tasked to hold at least one activity in the school (for instance produce a play, speak at public function, organise a competition).
- A local support group is formed under the aegis of the Epilepsy Support Foundation.

### **6.3.3 “C” and “D” receive health education campaign**

As for 6.3.2.

### **6.3.4 “A” receives health education campaign**

As for 6.3.2.

### **6.3.5 Monitoring**

This intervention will be monitored by

## 7. OUTCOME MEASURES

The key outcomes for all the of the Global Campaign's demonstration projects are a reduction in the treatment gap and in the burden of epilepsy. The means of gathering this data will be provided in the prevalence surveys at the beginning and end of the project and through the measures devised by the ILAE and included in Appendix 2 .

More specifically, the project in Zimbabwe will also seek to achieve the following:

- The availability of phenobarbitone in health centres increases to 80%
- The number of people receiving AEDs regularly increases by 50%
- Knowledge and attitudes about epilepsy in the community increases by 80%
- One staff member is trained in epilepsy treatment at every health centre
- 50% of people with epilepsy feel that their quality of life has improved

### Research tools

#### Prevalence Survey

Unique ID: \_\_\_\_\_ District Division (A, B, C or D): \_\_\_\_\_

Name: \_\_\_\_\_ Sex: \_\_\_\_\_ Age: \_\_\_\_\_ Birthday: \_\_\_\_\_

Occupation: \_\_\_\_\_

Address: \_\_\_\_\_ Householder: \_\_\_\_\_

#### Questionnaire:

1. Have you ever had attacks of shaking of the arms or legs which you could not control?
2. Have you ever had attacks in which you fall and become pale?
3. Have you ever lost consciousness?
4. Have you ever had attacks in which you fall with lost consciousness?
5. Have you ever had attacks in which you fall and bite your tongue?
6. Have you ever had attacks in which you fall and lose control of your bladder?
7. Have you ever had brief attacks of shaking or trembling in one arm or leg or in face?
8. Have you ever had attacks in which you lose contact with the surroundings and experience abnormal smells?
9. Have you ever been told that you have or had epilepsy or epileptic fits?
10. Have you ever had attacks in which you lose contact with your surroundings and experience a sensation in which objects change shape or size?
11. Did you ever have attacks of convulsions in fever before the age of 5?
12. Have you ever suddenly in a daze or amazement, lost something from your hand during an activity, writing or eating?
13. Have you ever had suddenly in a daze, smack, purposeless activity of hands which you subsequently have no memory?

**For those with definite or possible epilepsy:**

1. Onset age: \_\_\_\_\_
2. Number of attacks:
  - Recent 1 year: ?=have attacks ( \_\_\_\_\_ times); ?=no attack
  - Recent 2 years: ?=have attacks ( \_\_\_\_\_ times); ?=no attack
  - Recent 5 years: ?=have attacks ( \_\_\_\_\_ times); ?=no attack
3. Are there any causes of attack?  
\_\_\_\_\_
4. Did the patient take any treatment?  
\_\_\_\_\_
  - (1) Never accepted any treatment: ? = Yes; ? = No
  - (2) If have accepted treatment, was this: ? = Western medicine; ? = Traditional medicine  
 Drug name and dosage: \_\_\_\_\_  
 Effect: 1 = Excellent; 2 = Good; 3 = No effect  
 Treatment assessment: 1 = Regular; 2 = Irregular
  - (3) Was any treatment received last week: ? = Yes; ? = No  
 Drug name and dosage: \_\_\_\_\_  
 Effect: 1 = Excellent; 2 = Good; 3 = No effect

Investigator: \_\_\_\_\_ Date: \_\_\_\_\_

**Check result:**

**Conclusion:** ?= Diagnose epilepsy; = Excluded epilepsy

**Seizure type:**

1. Simple Partial Seizures
2. Complex Partial Seizures
3. Secondarily Generalised Seizures
4. Generalized Tonic-clonic seizures
5. Absences
6. Others ( Myoclonic, Atonic etc)

**Checked by Dr:**

**Date:**

## Quality of Life Questionnaire

### Study Variables

#### 1. The population and treatment characteristics

- Age of onset
- Sex
- Years of education
- Ethnicity

#### 2. The treatment

- Who provided the treatment?
  - village doctor
  - rural physician
- Where?
  - name of village/province
  - name of city/province
- Services and procedures performed during visit?
  - diagnostic procedures
  - physical and or mental examination
  - patient and family interview
  - referrals
  - other

#### 3. Immediate effects of treatment

- Seizure frequency per month
- Perceived seizure severity
  - none/mild
  - moderate
  - severe
- Side effects
  - mild
  - moderate
  - severe

#### 4. Functional impact of treatment

- Work status in the last month
  - not working in last month
  - number of hours working less than 10 hours
  - number of hours working between 10 and 20 hours
  - number of hours working between 20 and 30 hours
  - number of hours working more than 30
- Salary earned in last month
  - no
  - yes
  - amount earned in the last month
- Training status in the last month

- no training in last month
- number of hours of training less than 10 hours
- number of hours of training between 10 and 20 hours
- number of hours of training between 20 and 30 hours
- number of hours of training more than 30 hours
- Type of training in the last month
  - formal academic training
  - special job training
- Intention to work
  - I am developing a work plan
  - yes
  - no
- Travel capability, in the last month I have been able to travel independently
  - yes
  - no
- Carer support
  - my carer is now not working because of my epilepsy
  - no
  - yes
- Work status of carer in the last month
  - not working in last month
  - number of hours working less than 10 hours
  - number of hours working between 10 and 20 hours
  - number of hours working between 20 and 30 hours
  - number of hours working more than 30
- Social and community activities
  - in the last month the number of hours on social and/or community activities
- Household contributions
  - in the last month the number of hours spent on household tasks (for example cleaning, shopping, etc.)

5. Perceived impact (the impact of epilepsy scale)

Does your epilepsy and its treatment affect:

A LOT            SOME            A LITTLE            NOT AT ALL            NOT APPLICABLE

1. Your relationship with your spouse/partner
2. Your relationship with other close members of your family
3. Your social life and social activities
4. Whether or not you are able to work in paid employment
5. The kind of paid work you can do
6. Your health overall
7. Your relationship with friends
8. The way you feel about yourself
9. Your future plans and ambitions
10. Your standard of living

**Health Services Survey**

a) Health Service Indicators

District

- Number of psychiatric nurses in district (No.)
- Substantive District Nursing Officer in post (Y/N)
- Provincial nursing officer or provincial psychiatric nurse has visited district in past 3 months (Y/N)
- DNO has visited clinic in past 3 months (Y/N)

Clinic

- PWE visits recorded in psychiatric register at clinic (Y/N)
- No. of seizures recorded in register at clinic (Y/N)
- Dose of drug recorded in register at clinic (Y/N)
- Clinic has procedure to follow up on defaulters (Y/N)
- Population covered by Clinic (No.)
- No. of PWE on register and/or no. of visits to clinic in past month (No.)
- Particular “epilepsy day” each month at clinic (Y/N)

b) Drug use indicators

District

- Percent antiepileptic drugs (AEDs) in stock at district hospital (%)
- District hospital pharmacist in post (Y/N)
- District hospital pharmacy technician in post (Y/N)
- District hospital pharmacy uses defined stock control procedure (Y/N)
- Percent AED stock cards accurate and up-to-date (%)
- Expired AEDs present on shelf (Y/N)

Clinic

- Phenobarbitone tablets in stock (Y/N)
- Stock control procedure in place (Y/N)
- Expired AEDs on shelf (Y/N)
- Stocks of carbamazepine or phenytoin present (Y/N)
- Mean and median daily phenobarbitone dose from 10 randomly selected PWE visits from the past month (No.)
- No. of PWE at clinic receiving carbamazepine or phenytoin (No.)

Hospital

- No. of admissions of status epilepticus (SE) in past 3 months (No.)
- Percent SE patients received EEG (%)
- Ave. No. of AEDs on discharge after SE (No.)
- Percent patients with AED blood level measured (%)

**KAP for Health Care Workers Questionnaire  
Instructions**

1. Please answer all questions
2. Circle one correct answer only
3. All questions carry equal marks

### Questions

- |    |  |  |        |
|----|--|--|--------|
| 1. | Epilepsy is due to                           | a) sudden excessive electrical discharge from nerve cells<br>b) emotional disturbances<br>c) bacterial infection |        |
| 2. | The commonest cause of epilepsy is           | a) brain tumour<br>b) reduced blood supply to the brain<br>c) no detectable cause                                |        |
| 3. | In general, epileptic attacks usually last   | a) several hours<br>b) several minutes<br>c) several days  |        |
| 4. | Epileptic seizures are now classified as     | a) major/minor<br>b) site of seizure origin in the brain<br>c) partial/generalised                               | p      |
| 5. | In complex partial seizures consciousness is | a) retained fully<br>b) partially disturbed<br>c) completely lost  | c      |
| 6. | Tongue biting and incontinence are common in | a) absence seizures<br>b) myoclonic seizures<br>c) tonic-clonic seizures   | t      |
| 7. | Absence seizures usually last for<br>8       | a) 15-20 seconds<br>b) 2-3 minutes<br>c) 30 minutes  |        |
| 8. | Absence seizures occur                       | a) several times daily<br>b) once a week<br>c) twice a month   | o<br>t |
| 9. | In complex partial seizures the patient      | a) always falls down unconscious   |        |



- b) has automatic behaviour such as chewing and lip-smacking  
c) always has limb jerking
10. In simple partial seizures there is  
a) twitching of one side of the body only  
b) loss of consciousness  
c) hallucinations
11. Hysterical seizures often occur  
a) when patient is alone  
b) during sleep  
c) in the presence of others
12. In hysterical seizures  
a) tongue biting is common  
b) tongue biting is very unusual  
c) urinary incontinence occurs
13. Febrile seizures are common  
a) in children of 6 months – 2 yrs  
b) in the 5 – 10 year age group  
c) in poorly nourished adults
14. During a tonic-clonic seizure you will  
a) thrust a spoon into the mouth  
b) hold the limbs down forcefully  
c) leave the patient alone
15. In status epilepticus  
a) seizures follow one another quickly, with unconsciousness between attacks  
b) seizures occur every other day  
c) one of the above
16. Drug treatment to terminate an epileptic seizure is needed  
a) for every attack  
b) if duration exceeds 15min  
c) in cases with incontinence
17. Drug choice for status epilepticus is  
a) phenobarbitone  
b) primidone  
c) diazepam

18. Apart from the oral and I.V. routes, diazepam can be given a) intranasally  
b) rectally  
c) intrathecally
19. Certain antiepileptic drugs (AEDs) are specific for certain seizures a) true  
b) false
20. Multiple drug therapy is useful in the treatment of TB, therefore it should also be useful in epilepsy a) true  
b) false
21. Restlessness or hyperactivity in children is most common with a) phenobarbitone  
b) phenytoin  
c) carbamazepine
22. Gum hypertrophy is usually seen with a) phenobarbitone  
b) phenytoin  
c) carbamazepine
23. Skin rashes can occur with AEDs a) true  
b) false
24. AEDs can cause birth defects if taken in the first trimester a) true  
b) false
25. Epilepsy occurs in a) 18% of the general population  
b) .5 – 3%
26. A common cause of status epilepticus is a) menstrual cycle  
b) full moon  
c) non-compliance with drugs
27. Febrile seizures are not the same as epilepsy a) true  
b) false
28. AED therapy is aimed at curing epilepsy a) true  
b) false
29. In epilepsy, drug treatment must be continued for a) one week, then review

- b) one year only  
c) at least 2 years
30. AEDs given by mouth usually become effective within  
a) few hours  
b) few days  
c) 4 weeks
31. With AED therapy, full seizure control can be obtained in  
a) 100% of cases  
b) 70-80% of cases  
c) 0-30% of cases
32. Once seizures are controlled, AEDs can be withdrawn after  
a) 4 weeks  
b) -12 months  
c) -5 years
33. Methods for increasing drug compliance  
a) scolding the patient properly  
b) linking the drug use to a daily activity e.g. breakfast  
c) putting the drugs in coloured envelopes
34. Breastfeeding epileptic women should be advised to feed their babies while sitting on the floor  
a) true  
b) false
35. Have you had a teaching session on epilepsy in the last six months ? Yes / No

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## Public Perceptions Towards Epilepsy Questionnaire

### Section 1

- 1) Where have you heard the most about epilepsy? (Please circle all that apply)
  - a. Independent study
  - b. Newspaper articles / magazines
  - c. Television
  - d. Doctors
  - e. Personal experiences with epilepsy
  - f. Never heard of epilepsy
  
- 2) I know about epilepsy because (please circle all that apply):
  - a. I currently or have had epileptic attacks
  - b. I have family members who have or had epileptic attacks
  - c. I know close friends who have epileptic attacks
  - d. I have read information about epilepsy
  - e. I have NO knowledge on epilepsy
  
- 3) How would you rate your knowledge on the signs and symptoms of epilepsy? (Please circle ONE)
  - a. Superior
  - b. Above Average
  - c. Average
  - d. Below Average
  - e. Poor
  
- 4) An individual with epilepsy is most likely helped by (please circle all that apply):
  - a. Mental health professional
  - b. General practitioner
  - c. Neurologist
  - d. Religious leader
  - e. Healer
  - f. Family
  - g. Self
  - h. Nobody
  
- 5) Have you ever witnessed an epileptic attack (seizure)?      Yes/No
  
- 6) Have you ever performed first-aid management for an epileptic attack?      Yes/No
  
- 7) Do you think that some of your students have epilepsy?      Yes/No
  
- 8) Are you interested in learning more about epilepsy?      Yes/No

## Section 2

- 1) Approximately, what percentage of epilepsy cases is controllable? (Please circle one)
  - a. 100%
  - b. 80%
  - c. 50%
  - d. 30%
  - e. 10%
  
- 2) What treatment is optimal for the control of epilepsy? (Please circle one)
  - a. Anti-epileptic medication
  - b. Prayer
  - c. Treatment from healers
  - d. Nothing
  
- 3) Why is it important to detect and treat epilepsy early on in the child? (Please circle one)
  - a. To prevent problems with learning
  - b. To avoid spread of contamination
  - c. To control the frequency and seriousness of the seizures later in life
  - d. All of the above
  - e. a and c only
  
- 4) What would you do if a person with epilepsy loses consciousness during a seizure? (Please circle one)
  - a. Pour cold water on his/her face
  - b. Try to awaken the person by shaking them
  - c. Put them on their side until they awake on their own
  - d. None of the above
  - e. All of the above
  
- 5) Which of the following is true about anti-epileptic drug treatment? (Please circle one)
  - a. It must be discontinued as soon as possible because it can be addictive
  - b. These medications should be taken regularly according to the doctor's advice
  - c. Medications are not effective for children with epilepsy
  - d. Control seizures with a more nutritious diet instead of anti-epileptic treatment
  - e. None of the above
  
- 6) What would you **NOT** do for a patient having an epileptic attack? (Please circle one)
  - a. Turn the individual on his/her side
  - b. Remove any sharp objects from the person
  - c. Place a hard object in the person's mouth
  - d. None of the above
  - e. Call the doctor
  
- 7) Which of the following assertions is FALSE about epileptic seizures? (Please circle one)
  - a. Convulsions are the only the way you can tell if the child has an epileptic seizure
  - b. Confusion in behaviour or slurred speech can also be signs of epileptic attacks

- c. Uncontrolled falling or jerking without loss of consciousness could also be an epileptic attack
- d. None of the above
- e. All of the above

8) If a child is having one epileptic seizure after another within 10-15 minutes, what would you do? (Please circle one)

- a. Call an ambulance or rush the child to the hospital
- b. Wait for the seizures to calm down by themselves before taking the child to the doctor
- c. Attempt to stop the convulsions
- d. Both a and c
- e. None of the above

9) Are convulsions the only manifestations of epilepsy? (Please circle one)

- a. Yes
- b. No

10) Is epilepsy a disease? (Please circle one)

- a. Yes
- b. No

11) Can epilepsy begin at any age? (Please circle one)

- a. Yes
- b. No

12) Is epilepsy contagious? (Please circle one)

- a. Yes
- b. No

13) Is epilepsy treatable? (Please circle one)

- a. Yes
- b. No

14) Which of the following can be causes for epilepsy? (Please circle one)

- A. Blows to the head Yes/No
- B. Bad thinking Yes/No
- C. An infection to the brain Yes/No
- D. High Fever Yes/No
- E. An evil spirit Yes/No
- F. Problems during child-birth Yes/No

### Section 3

Statements	Strongly Agree	Agree	No Opinion	Dis-agree	Strongly Disagree
1. There should be more dissemination of knowledge about epilepsy.					
2. Having epilepsy is a sign of being a failure in life.					
3. I would not like to have a child with epilepsy in the classroom					
4. Epilepsy is a treatable condition.					
5. Epilepsy should be treated by neurologists.					
6. I would feel comfortable in allowing my child to marry a person with epilepsy.					
7. Individuals with epilepsy can occupy leadership positions in the community.					
8. Too much suffering and grieving during childhood can lead to epilepsy.					
9. People with epilepsy cannot have a normal family life.					
10. Individuals with epilepsy can contribute to society as much as individuals without epilepsy.					
11. It is best to isolate the individual with epilepsy.					
12. I would feel comfortable in allowing my child to sit/play with a child with epilepsy					
13. Individuals with epilepsy are responsible for causing their condition.					
14. A majority of children with epilepsy have lower than average intelligence.					
15. I prefer that students with epilepsy go to special schools.					
16. Individuals with epilepsy are at a higher risk for becoming insane later in life.					
17. Epilepsy can be treated at the primary care level.					
18. Anti-epileptic medications should not be taken for a long time because they are addictive.					
19. I would want individuals with epilepsy to be hired as teachers.					
20. Epilepsy can be treated effectively by traditional healers.					





### Logical Framework Analysis for Management and Monitoring of Project

Narrative Summary	Objectively Verifiable Indicators/Budget	<i>Means of Verification</i>	Responsible Parties	Assumptions
<p>1. <b>Goal of Global Campaign:</b>                  2. To reduce the epilepsy treatment gap and the socio-economic burden of epilepsy</p>	<p>3.                  h) The treatment gap in developing countries is reduced from 85% to 50%                  4. ii) The burden of epilepsy decreases by 50%</p>	<p>5.                  6. Prevalence, treatment &amp; quality of life surveys in developing countries</p>	<p>7.                  8. Secretariat of Global Campaign</p>	<p>9.                  10. WHO and governments continue to act on commitments</p>
<p>11. <b>Purpose of Project</b> (what the Project 'achieves'):                  12. To improve the quality of life of people with epilepsy in rural Zimbabwe</p>	<p>13.                  14. Quality of life increases for ?% of people with epilepsy in study area</p>	<p>15.                  16. Results of three final surveys (after 12 months of interventions) in Project's Final Report to Scientific Project Leaders</p>	<p>17.                  18. Dr Jens Mielke</p>	<p>19. <b>Purpose to Goal:</b>                  20. Other nations take up the approach/ insights of the Project                   21. Long-term funds are available</p>
<p>22. <b>Outputs</b> (what the Project 'produces'):                  1) Figures for the prevalence of epilepsy and its treatment gap.                   2) Information on the effect of epilepsy on the quality of life of people with epilepsy.</p>	<p>23.                  24. 1i) The number of people with epilepsy/1,000 is calculated.                  25. 1ii) The number of people with epilepsy not receiving appropriate treatment is calculated                   26. 2) Data on the impact of epilepsy is collected from people with epilepsy                   27. 3i) The availability of phenobarbitone in health centres increases to 80%</p>	<p>32.                  33. 1-4) Quarterly reports to Scientific Project Leaders (from 2<sup>nd</sup> quarter onwards)</p>	<p>34.                  35. ?WHO</p>	<p>36. <b>Outputs to Purpose:</b>                  37. The political situation in Zimbabwe does not worsen                   38. AED supplies continue to be available</p>

<p>3) A pharmaco-economic intervention improves the physical quality of life of people with epilepsy</p> <p>4) A psychosocial intervention improves the social quality of life of people with epilepsy</p>	<p>28. 3ii) The number of people receiving AEDs regularly increases by 50%</p> <p>29. 4i) Knowledge and attitudes about epilepsy in the community increases by 80%</p> <p>30. 4ii) One staff member trained in epilepsy treatment at every health centre</p> <p>31. 4iii) ?% of people with epilepsy feel that they are more accepted by their communities</p>			<p>39. Education of health workers and community continues to be remembered</p> <p>40. ?Any others</p>
<p>41. <b>Activities</b> (what the Project ‘does’):</p> <p>42. 1a) Training of surveyors</p> <p>43. 1b) Initial survey of population for prevalence and treatment gap</p> <p>44. 1c) Prevalence and treatment survey after 6 months</p> <p>45. 1d) Prevalence and treatment survey after 12 months</p> <p>47. 2a) Training of surveyors</p> <p>48. 2b) Initial survey of quality of life of people with epilepsy</p> <p>49. 2c) Survey of quality of life of people with epilepsy after 6 months</p> <p>50. 2d) Final survey of quality of life of people with epilepsy, after 12 months</p> <p>51. 3a) Initial health system survey</p> <p>52. 3b) “A” receives pharmaco-economic programme for 6 months</p>	<p>61.</p> <p>62. 1a) ?people attend workshop, costing US \$ 1,000</p> <p>63. 1b) ?people surveyed, costing US \$ 6,430</p> <p>64. 1c) ?people surveyed, costing US \$ ?</p> <p>65. 1d) ?people surveyed, costing US \$ ?</p> <p>66. Will this training and survey take place at same time as for other surveys below and be carried out by same people and within the US\$7,430?</p> <p>67. 2a) ?people attend workshop, costing US \$ ?</p> <p>68. 2b) All those identified with epilepsy in 1b receive questionnaire, costing US \$ ?</p> <p>69. 2c) All those who participated in 2b receive questionnaire, costing US \$ ?</p> <p>70. 2d) As for 2c, costing US \$ ?</p> <p>71. 3a) ?clinics complete survey, costing US \$ ?</p> <p>72. 3bi) ?visits to clinics and provided with AEDs where necessary, costing US \$ ?</p> <p>73. 3bii) ?attendance/clinic records for people</p>	<p>89.</p> <p>90. 1a&amp;b) 1<sup>st</sup> quarterly report to Scientific Project Leaders</p> <p>91. 1c) 3<sup>rd</sup> quarterly report to Scientific Project Leaders</p> <p>92. 1d) 5<sup>th</sup> quarterly report to Scientific Project Leaders</p> <p>93. 2a&amp;b) 1<sup>st</sup> quarterly report to Scientific Project Leaders</p> <p>94. 2c) 3<sup>rd</sup> quarterly report to Scientific Project Leaders</p> <p>95. 2d) 5<sup>th</sup> quarterly report to Scientific Project Leaders</p> <p>96. 3a) 1<sup>st</sup> quarterly report to Scientific Project Leaders</p> <p>97. 3b) 2<sup>nd</sup> &amp; 3<sup>rd</sup> quarterly reports to Scientific Project Leaders</p>	<p>107.</p> <p>108. ?W ho</p>	<p>109. <b>Activities to Outputs:</b></p> <p>110. Political stability</p> <p>111. People willing to talk openly and honestly about their epilepsy</p> <p>112. Clinics prepared to be honest about their activities/resources</p> <p>113. AED prices do not rise to make them prohibitively expensive</p> <p>114. The community are willing to be honest</p>

<p>53. 3c) Health system survey after 6 months</p> <p>54. 3d) “B”, “C” &amp; “D” receive pharmaco-economic programme after 6 months and for 6 months</p> <p>55. 3e) Final health system survey, after 12 months</p> <p>56. 4a) Initial public perceptions of epilepsy survey</p> <p>57. 4b) “B” receives health education programme for 6 months</p> <p>58. 4c) Public perceptions about epilepsy survey after 6 months</p> <p>59. 4d) “A”, “C” &amp; “D” receive pharmaco-economic programme after 6 months and for 6 months</p> <p>60. 4e) Final public perceptions survey, after 12 months</p>	<p>with epilepsy collected, costing US \$ ?</p> <p>74. 3biii) ?clinic stock records retrieved, costing US \$ ?</p> <p>75. 3biv) Costs of treating people with epilepsy estimated, costing US \$ ?</p> <p>76. 3bv) ?focus group discussions take place regarding AEDs, side-effects and supply, costing US \$ ?</p> <p>77. 3c) As for 3a, costing US \$ ?</p> <p>78. 3d) As for 3bi-v, costing US \$ ?</p> <p>79. 3e) As for 3a, costing US \$ ?</p> <p>80. 4a) ?questionnaires completed, costing US \$ ?</p> <p>81. 4bi) ?PHCNs &amp; ?EHTs attend workshop, costing US \$ ?</p> <p>82. 4bii) All the above PHCNs &amp; EHTs provide information about epilepsy ?villages &amp; ?schools, costing US \$ ?</p> <p>83. 4biii) ?teachers attend epilepsy seminar and hold event at school, costing US \$ ?</p> <p>84. 4biv) A local support group established, costing US \$ ?</p> <p>85. 4c) As for 4a, costing US \$ ?</p> <p>86. 4d) As for 4bi-v, costing US \$ ?</p> <p>87. 4e) As for 4a, costing US \$ ?</p> <p>88. TOTAL BUDGET = US \$ ?</p>	<p>98. 3c) 3<sup>rd</sup> quarterly report to Scientific Project Leaders</p> <p>99. 3d) 4<sup>th</sup> &amp; 5<sup>th</sup> quarterly reports to Scientific Project Leaders</p> <p>100.3e) 5<sup>th</sup> quarterly report to Scientific Project Leaders</p> <p>101.4a) 1<sup>st</sup> quarterly report to Scientific Project Leaders</p> <p>102.4b) 2<sup>nd</sup> &amp; 3<sup>rd</sup> quarterly reports to Scientific Project Leaders</p> <p>103.4c) 3<sup>rd</sup> quarterly report to Scientific Project Leaders</p> <p>104.4d) 4<sup>th</sup> &amp; 5<sup>th</sup> quarterly reports to Scientific Project Leaders</p> <p>105.4e) 5<sup>th</sup> quarterly report to Scientific Project Leaders</p> <p>106. Budget monitored through quarterly reports to Scientific Project Leaders</p>	<p>about their views towards people with epilepsy</p> <p>115. Community and health workers put into practice their new KAP</p> <p>116. ?Any others</p>
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**Appendix 2 Possible activities of GCAE Zimbabwe: 2010 onwards**

GCAE objective	Proposed activities in Zimbabwe	Possible sources of support
Increase public and professional awareness of epilepsy as a universal, treatable brain disorder;	Training of professionals e.g. use workshops IEC material production and distribution Public media awareness programmes e.g. daily slots	WHO ILAE IBE MoH Corporates UNICEF
Raise epilepsy to a new plane of acceptability in the public domain;	Reduce stigma and misunderstanding- use the media Lobbying and advocacy Involve religious groups (normally they treat epilepsy as demons or possessions) Involve African healers Awareness programmes to address epilepsy and: Marriage, Women and pregnancy, Employment Schooling, Driving, Children HIV/AIDS Justice system e.g. offenders with diminished responsibility due to automatisms)	ILO WHO UNDP UNAIDS NAC UNIFEM MoEducation MoLabour MoSocial Welfare ESF ZLAE
Promote public and professional education about epilepsy;	Educate tutors and lecturers Educate health workers Ensure curriculum for health and social workers covers epilepsy adequately	
Identify the needs of people with epilepsy on a national and regional basis;	Get the needs from people with epilepsy (PWE) in Zimbabwe from different sectors Benchmark with results from SADC countries Incorporate epilepsy in the survey being planned by MoH	
Encourage governments and departments of health to address the needs of people with epilepsy	Ensure training Ensure adequate resources Ensure adequate literature e.g. on prevention	

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