

# Epilepsy in Latin America

Technical document based on presentations at the international workshop held in Santiago, Chile, in August 2013, plus subsequent contributions





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Produced by the Mental Health and Substance Use Unit of the Pan American Health Organization (PAHO), with the support of the Chilean League Against Epilepsy, the School of Medical Sciences of the National Autonomous University of Honduras, the International League against Epilepsy (ILAE), and the International Bureau for Epilepsy (IBE).

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## PREFACE

Epilepsy is one of the most common chronic neurological disorders worldwide, and affects millions of people in the Region of the Americas. However, there is a treatment gap of 50% in Latin America and the Caribbean (LAC).

There are simple, cost-effective treatments that can be handled at the primary care level, enabling the great majority of persons with epilepsy to live normal lives. However, one of the key problems confronting the Region's health systems is the fact that primary care teams lack the capacity to identify and manage epilepsy cases. At the same time, epilepsy continues to be a disease that can lead to stigmatization, discrimination, and exclusion.

Recognizing the burden that epilepsy and the existing treatment gap represent for LAC countries, in 2011 the 51st Directing Council of the Pan American Health Organization (PAHO) adopted the Strategy and Plan of Action on Epilepsy. The resolution approved by PAHO's Member States emphasized that this is an "important public health problem."

In the context of activities to support implementation of the Regional Strategy, a Latin American Workshop was held in August 2013 in Santiago, Chile, to discuss and share views concerning successful experiences in Latin America in the field of epilepsy, learn from those initiatives, and assess the feasibility of implementing them in other countries of the Region.

This technical document is a compilation of the main presentations given at the workshop in Chile, revised and updated by their authors for this publication, with additional contributions incorporated. PAHO is making this document publicly available on its website.

The Sixty-eighth World Health Assembly, which met in May 2015, approved the report "Global burden of epilepsy and the need for coordinated action at the country level to address its health, social, and public knowledge implications." This was a highly important step toward putting epilepsy on the global public health agenda.

In August 2015, in Tegucigalpa, Honduras, PAHO held a second Latin American Workshop on epilepsy. The workshop provided an opportunity to follow up on implementation of the Regional Strategy at the country level, as well as to discuss progress achieved and upcoming challenges. The event concluded with concrete agreements that will be subject to monitoring and control. The corresponding technical document was formally presented at the end of the workshop.

Dr. Carissa Etienne, Director of PAHO, has clearly expressed the Organization's commitment to cooperating with the Member States to improve the care of persons with epilepsy, and this exercise in discussing the most positive and innovative experiences in Latin America is an important step in that process. The task of improving the quality of life and protecting the rights of persons with epilepsy has advanced in the Region, but major challenges remain to be

addressed in an integral and collaborative manner. The Strategy adopted by the PAHO Directing Council should become a tool in efforts to improve health systems' response to epilepsy.

Finally, thanks are due to the authors who wrote the various chapters of this document, and to the Chilean League against Epilepsy, which made the initial compilation of the presentations given at the August 2013 workshop. As usual, the process of creating the document has had the ongoing support of PAHO partners at ILAE and IBE, as well as of the World Health Organization's Department of Mental Health and Substance Abuse. Special thanks go out to the School of Medical Sciences of the National Autonomous University of Honduras, to that country's Ministry of Health, and to PAHO's Country Office for serving as exemplary hosts of the Regional Workshop.

This technical document is presented in hopes that it will prove a source of learning and serve as a useful, practical tool for health authorities and workers in the field, as well as for interested members of the public.

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# I

## INTRODUCTION

Editors

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Epilepsy is a neurological disorder of great importance in terms of its impact on society and health in Latin America and the Caribbean (LAC). It can be clinically diagnosed without specialized expertise, e.g., in primary health care facilities. The great majority of people with epilepsy can lead normal lives if they receive appropriate treatment. However, various factors limit and impede treatment. These include lack of information, stigmatization, and insufficient access to health services.

In 2008, the Pan American Health Organization (PAHO), the International League against Epilepsy (ILAE), and the International Bureau for Epilepsy (IBE) jointly published the first Report on Epilepsy in Latin America and the Caribbean, an initial effort to shed light on the situation in LAC countries, despite the lack of data sources available at that time.

In September 2011, PAHO's 51<sup>st</sup> Directing Council adopted the Strategy and Plan of Action on Epilepsy. This was a highly significant event, since it was the first time that all PAHO Member States came together to discuss the subject of epilepsy, designating it as a priority, and approving a strategic plan, with a roadmap for the next ten years. The relevant resolution of the Directing Council can be found in the annexes at the end of this document. The Plan calls for action in the following areas:

1. Programs and legislation to provide care for persons with epilepsy and to protect their human rights.
2. A network of health services to care for persons with epilepsy, with emphasis on primary health care and the provision of drugs.
3. Public awareness and education, including for people with epilepsy and their families.
4. Strengthening the capacity to produce, evaluate, and use information on epilepsy.

A Latin American workshop on epilepsy was held in August 2013 in Santiago, Chile. The purpose of the meeting was to discuss successful and innovative experiences in Latin America, learn from those initiatives, and assess the possibilities of implementing them in other countries, as well as to gain a better understanding of local realities that facilitate or impede implementation of the regional Plan of Action.

The workshop was highly productive in terms of learning and analysis, and provided extensive opportunity for the participants to share their views. In the final session, participants reflected on a number of key elements. It was noted that resources for the care of epilepsy in the Region



are generally scarce, particularly in comparison with the resources allocated to other health problems. It would therefore be advisable to focus on a small group of priority objectives involving high-impact interventions. The dispersed nature of past efforts has been one of the chief causes of the limited results of many of the initiatives designed to improve care for epilepsy sufferers. It was also noted that actions are frequently implemented with no provision for measuring their real impact, and with a very poor cost-benefit ratio.

The second epilepsy report, published in 2013, was far more complete than the previous one, providing a compilation of available data on resources, programs, and services relating to the care of persons with epilepsy in 25 LAC countries. The report also detailed information on mortality.

This technical document includes the principal presentations made at the workshop in Chile, updated and revised by their authors and edited by the workshop editorial group. Other more recent contributions have also been included. In 2015, there was an opportunity to meet again, this time in Tegucigalpa, Honduras, to follow up on the process, analyze advances made, and discuss pending issues and new challenges. A summary of that event appears in the annexes to this document.

The reader should bear in mind that this document is a compilation of a range of presentations and contributions, covering experiences at different times in different countries with varying methodologies. The presentations take a variety of approaches, and sometimes reflect the particular points of view of their authors (which are not necessarily shared by all). The subjects range from the development of national programs, legislation, and education to epidemiological research. This diversity is, in a positive sense, an expression of the multiplicity of efforts underway, and of the different paths that the Region's countries are following.

This report appears in summary form in Chapter II, below, and is an essential element in the implementation of the regional strategy and plan, in that it defines the current situation and provides a baseline for action. The chapter is supplemented by a brief preliminary report (2014) of the WHO Project Atlas on neurological disorders.

Chapter II, by WHO consultant Tarun Dua, presents a global perspective on epilepsy, explaining the epidemiological and social magnitude of the problem from a public health perspective, and issuing a call for action.

Chapters IV and V are devoted to Chile's experience, which is a regional model. Since 2002, Chile has had a National Epilepsy Program, and epilepsy is included as a priority in the country's Universal Health Guarantee Plan. These chapters also detail the design and implementation of the Ministry of Health's clinical practice guides.

The School of Medicine of the National Autonomous University of Honduras has a long history of epidemiological research on epilepsy, including the design of interventions to reduce the treatment gap. Chapter VI covers this information.

Mexico's Priority Epilepsy Program is another valuable experience in the Region. It emphasizes two lines of work: the creation of 65 specialized care centers and the strengthening of the primary care system.

The E-Jaguar website, developed in Brazil with a view to providing regional information, is a field experiment in communicating scientific information to the general population. It was conceived as a tool to improve health care and quality of life for people with epilepsy, and is the subject of Chapter VIII.

Colombia and Argentina have passed legislation on epilepsy and are currently working resolutely on implementation. Experience in this area, and the legislative texts themselves, can serve as an example to other States interested in the issue. Chapter IX addresses this topic.

Continuing education for medical professionals is a key element of the Regional Strategy. Chapter X explores this subject, based on the experience of Uruguay and ILAE, presenting a number of ideas on how to approach this component at the regional level.

Chapter XI summarizes a report on taeniasis and neurocysticercosis presented at the 2015 Regional Epilepsy Workshop in Tegucigalpa, Honduras.

Finally, Chapter XII summarizes the fundamental elements discussed in the different chapters, and considers future opportunities and challenges.

PAHO, ILAE, and IBE, as partners, are firmly committed to supporting the countries in their efforts to place epilepsy on the public sector's health agenda, encouraging effective implementation of relevant programs and legislation, and strengthening the role of civil society, with a particular focus on user groups and family members. This technical document is part of the effort to disseminate best practices and lessons learned. The hope is that it will be useful to all people working in this field.

### **Recommended reading:**

1. Pan American Health Organization. Strategy and Plan of Action on Epilepsy. Fifty-first Directing Council of PAHO, Sixty-third Session of the WHO Regional Committee for the Americas, 26-30 September 2011. Document CD51/10 and Resolution CD51.R8. Washington, DC: PAHO; 2011 [accessed 29 May 2015]. Available at: <http://new.paho.org/hq/dmdocuments/epilepsy%20doc.pdf>. <http://www.epilepsysocu.sld.cu/docs/plan%20estrategico%20epilepsys.pdf>

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## II

### A GLOBAL PERSPECTIVE ON EPILEPSY: IMPROVING ACCESS TO CARE

Tarun Dua, World Health Organization (WHO, Geneva)  
Brooke Short, World Health Organization (WHO, Geneva)

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#### I. Why is epilepsy a priority?

- Epilepsy is a noncommunicable brain disorder that affects individuals of all ages. Approximately 50 million people worldwide live with epilepsy, making it one of the most common neurological diseases at the global level (29).
- Around 80% of individuals with epilepsy live in low- and middle-income countries (1).
- Premature death is up to three times greater among epileptics than in the general population, with the highest rates in low- and middle-income countries, and with higher rates in rural areas than in urban areas (2, 3).
- Discrimination against persons with epilepsy is reflected in problems in education, employment, marriage, and social relations.
- Epilepsy is responsible for approximately 20.6 million disability-adjusted life years (DALYs) (0.75% of the global burden) (4).
- Epilepsy has high economic cost – an estimated cost in Europe, for example, of more than €20 billion annually (5).

#### II. Incidence and prevalence

Worldwide, around 2.4 million people are diagnosed with epilepsy each year. Currently, the estimated proportion of the population with active epilepsy (recurring convulsions or need for treatment) is between 4 and 10 per thousand inhabitants. However, some studies in low- and middle-income countries suggest a much higher proportion of 7-14 per thousand (6).

In high-income countries, the number of new cases annually in the general population is between 30 and 50 per 100,000 inhabitants. In low- and middle-income countries, this figure can be as much as twice as high (7), probably due to the growing risk of endemic conditions such as malaria and neurocysticercosis (NCC) (8), a higher incidence of traffic accidents, injuries at birth, variations in the quality of medical infrastructure, availability of preventive health programs, and accessibility of care (9, 10, 11).

### III. Mortality and comorbidity

- Individuals with convulsions tend to have more physical problems (such as fractures and hematomas from convulsion-related injuries), as well as higher rates of psychological conditions such as anxiety and depression (12).
- In low- and middle-income countries, premature mortality is approximately three times greater than in the general population in developed countries.
- There is circumstantial evidence of even higher (by a factor of six) mortality rates in some developing countries.
- Related causes of death include accidents, self-inflicted injuries and suicide, epileptic states, sudden unexpected death in epilepsy (SUDEP), and high psychiatric comorbidity (13).
- Considering only SUDEP, epilepsy ranks second among selected neurological illnesses, after cerebrovascular accidents, in terms of years of potential life lost (YPLL) (14).

### IV. Stigma

Although social effects vary from country to country, the discrimination and social stigma surrounding epilepsy around the globe are often more difficult to overcome than the convulsions themselves. In most countries, people's knowledge of epilepsy, and their attitudes towards it, is poor in all age groups. Stigma is multi-faceted and can affect people with epilepsy in various areas and stages of life. Examples include children being unable to attend school and adults having difficulty obtaining and keeping jobs. The phenomenon can also extend beyond affected individuals, to members of their families and other people close to them. The stigma associated with this disorder can discourage people from seeking treatment for the symptoms, due to the fear of being identified with the disease.

Among other constraints, persons with epilepsy may be the target of prejudice, resulting in reduced access to health care and life insurance, difficulty in obtaining a driver's license, and obstacles to entering certain occupations. Legislation in many countries reflects centuries of misunderstanding of epilepsy, as illustrated by the following examples:

- In China and India, epilepsy is commonly seen as a reason for prohibiting or annulling marriage.
- A law in the United Kingdom prohibiting persons with epilepsy from marrying was repealed as recently as 1970 (15, 16).
- Until the 1970s in the United States, it was legal to deny persons with convulsive crises access to restaurants, theaters, recreational centers, and other public buildings (17).

There is no current consensus regarding the measurement of community attitudes and stigma associated with epilepsy. There is a need for well-designed studies to examine interventions that address the stigma. Public awareness and advocacy campaigns are crucial if stigma and discrimination are to be reduced.

## V. Treatment

Epilepsy treatment, through daily medication, can be easy and affordable, at a cost of only US\$5 a year. Recent studies in low- and middle-income countries have shown that up to 70% of children and adults with epilepsy can be treated successfully, i.e., their attacks can be completely controlled with antiepileptic drugs (AEDs) (18). Moreover, after two to five years of successful treatment without attacks, drugs can be withdrawn in around 70% of children and 60% of adults, without subsequent side effects (19, 20, 21).

The drugs involved (valproic acid, phenobarbital, phenytoin, and carbamazepine) are effective and cost-effective, and are on most of the countries' lists of essential medicines. Extending treatment to 50% of persons with epilepsy could reduce the current disease burden associated with epilepsy by nearly one third (22).

According to a comparative analysis of national lists of essential drugs conducted in 2012 with 109 countries, 96% of the countries included phenobarbital, 95% carbamazepine, 83% phenytoin, and 92% valproic acid (23). However, the availability and affordability of generic antiepileptic medicines in the public sector continues to be below 50% at the global level (24). A study by Cameron et al. in 2012 observed that:

- In comparison with international reference prices, per-patient prices in the public sector were higher by factors ranging from 4.95 to 17.50; per-patient prices in the private sector were higher by factors of 11.27 to 24.77; and prices of original brand-name products were approximately 30 times higher.
- In terms of affordability, a minimum-wage government worker would need between one and 2.6 days of wages to pay for one month of treatment with phenytoin, and between 2.71 and 6.20 days of wages to pay for carbamazepine (24).

## VI. The treatment gap

The treatment gap is defined as the proportion of persons with epilepsy who receive no type of care from health services (25). A systematic review in 2009 (covering 74 studies) showed a treatment gap above 75% in low-income countries, and over 50% in most medium- and high-income countries, while many high-income countries have gaps below 10%. The therapy gap is significantly higher in rural areas (relative risk (RR): 2.01; confidence interval (CI) 95%: 1.40-2.89) and in lower-income countries as defined by the World Bank (RR: 1.55; 95% IC: 1.32-1.82) (1).

Factors related to the treatment gap can be categorized as follows:

- Supply: Lack of infrastructure and provision of services for epilepsy care, insufficient skilled human resources for diagnosis and treatment of the disease, and high cost and insufficient availability of antiepileptic drugs.

- Demand: Superstitions and cultural beliefs that affect decisions to seek care, community preferences for traditional/alternative medicine and faith-based healing, poor education on epilepsy, and lack of adherence to medical treatment.
- Health economics: Health budgets may fail to include epilepsy, and health care plans may be inadequate.
- Policies: Failure of national health policies to make epilepsy a priority.

## VII. Social and economic impact

Epilepsy represents 0.75% (26) of the global disease burden. This measure is a combination of years of potential life lost (YPLL) due to premature mortality and years lived with less than desirable health. In 2010, at the world level, epilepsy was responsible for approximately 17.4 million disability-adjusted life years (DALY), and ranked 20<sup>th</sup> as a cause of years lived with disability (26). Epilepsy has significant economic implications in terms of needs for health care, premature death, and loss of labor productivity. A 1998 Indian study estimated the per-patient cost of treating epilepsy to be as high as 88.2% of the country's per capita GDP, and estimated the overall costs related to epilepsy, including medical expenditures, travel, and lost time at work, to be over US\$1.7 billion a year (27).

## VIII. Challenges and gaps in epilepsy care

1. Limited capacity of health systems and inequitable distribution of resources
2. Lack, or very serious lack, of trained personnel
3. Inadequate access to affordable medicines
4. Social ignorance and false notions
5. Poverty
6. Continuing low-priority status in many countries

## IX. The history of international efforts to improve epilepsy care

- 1997 – WHO and two international non-governmental organizations (NGOs)—ILAE and IBE—launch the global campaign against epilepsy, “Out of the Shadows.”
- 2000-2004 – Pilot “Out of the Shadows” project in China. Findings indicate that trained primary care physicians can diagnose and treat epilepsy, and that this care model can significantly reduce gaps in epilepsy treatment while lowering the costs associated with the disease.
- 2005 – WHO publishes *Atlas: Epilepsy Care in the World*.
- 2008 – Launch of WHO's global Mental Health Gap Action Program (mhGAP), designed to improve care for mental, neurological, and substance abuse disorders, including epilepsy.
- 2011 – The Region of the Americas (PAHO/WHO) approves the Strategy and Plan of Action on Epilepsy for 2012-2021.
- 2011 – The European Parliament approves the European Union's declaration on epilepsy.

- 2011 – The WHO program to reduce the epilepsy treatment gap begins with pilot projects in Ghana and Vietnam.
- 2012 – Report of the Institute of Medicine: Epilepsy across the spectrum: Promoting health and understanding.
- 2012 – The WHO program to reduce the treatment gap extends its pilot projects to Myanmar and Mozambique.
- 2014 – An international workshop to improve access to antiepileptic drugs (AEDs) is held in Italy.
- 2015 – The World Health Assembly adopts Resolution WHA68.20 “Global burden of epilepsy and the need for coordinated action at the country level to address its health, social, and public knowledge implications.”

## **X. Improving epilepsy care: What is needed?**

The World Health Assembly’s recent adoption of Resolution WHA68.20, “Global burden of epilepsy and the need for coordinated action at the country level to address its health, social, and public knowledge implications,” offers a historic opportunity to improve care for epilepsy around the world. WHA68.20 urges the countries to strengthen effective leadership and governance for general health, mental health, and NCD policies, including consideration of the specific needs of persons with epilepsy. These measures include:

1. Effective leadership and governance:
  - Legislators and policy makers develop and allocate financial and human resources to implement national programs for epilepsy care.
  - Public health policies and strategies are developed to prevent epilepsy, such as promotion of safe pregnancy and delivery, control of cysticercosis, and prevention of cranial trauma and cerebrovascular accidents.
  - Legislators modify existing legislation to promote the rights and opportunities of persons with epilepsy.
2. Improving the treatment of epilepsy:
  - Public health policies on general health, mental health, and NCDs, including care for persons with epilepsy.
3. Integrating the management of epilepsy in primary care:
  - Training non-specialized health care personnel to diagnose and treat epilepsy.
  - Providing training that recognizes the medical and social needs associated with the disease.
  - Giving consideration to integrating epilepsy services with mental health services and other existing NCD programs.
4. Improving the accessibility and affordability of safe antiepileptic drugs.
5. Improving knowledge:
  - Awareness building and education on epilepsy in schools and communities to reduce stigma and false notions about the disease.



- Educating persons with epilepsy, their families, and health workers to recognize the disease and take measures to implement treatment.
  - Improving and promoting efforts to measure community attitudes and stigma associated with epilepsy.
6. Enhancing investment:
- Strengthening health information and surveillance systems, and improving the evaluation and monitoring of epilepsy.
  - Investing in building national capacity.
  - Developing standardized research tools to identify the social and economic benefits of treating epilepsy.
7. Collaboration with community partners: Supporting national organizations concerned with the care and protection of persons with epilepsy.

## **XI. Mental Health Gap Action Program (mhGAP).**

WHO created the Mental Health Gap Action Program (mhGAP), which is designed to improve care for mental, neurological, and substance abuse disorders. The mhGAP program is part of the Global Mental Health Action Plan approved by the World Health Assembly in 2013. Epilepsy is one of the priority medical conditions defined in the program. The mhGAP Intervention Guide (GI-mhGAP) was produced to facilitate the implementation of evidence-based interventions, in order to identify and manage a series of priority disorders in non-specialized care contexts.

The basic premises of mhGAP involve reducing the mental disease burden and the gap in budgeting for mental health; encouraging the rational organization of mental health services; improving the coverage of services for the population; and ensuring that abuses and violations of human rights are stopped.

The primary beneficiaries of mhGAP are persons with mental, neurological, and substance abuse disorders, including epilepsy. Other beneficiaries are:

- Ministries of health, policy makers, and legislators;
- Non-specialized medical personnel (doctors and nurses), specialists, health planners, and traditional healers;
- National stakeholders: NGOs, national experts, and universities and academic centers; and
- International stakeholders: organizations, foundations, the private sector, WHO, and others.

The mhGAP strategy is based on:

- Non-specialized personnel at the primary and secondary care levels receiving supervision, support, and education from specialists (mental health professionals and neurologists);
- Participation of nurses and community health agents, where applicable;
- Participation of traditional and faith-based healers;

- Participation of self-help groups and user groups, and NGOs;
- Attention to undergraduate and graduate curricula; and
- Strengthening of health systems: referral, supervision, and provision of drugs.

The mhGAP evaluation framework covers:

- Training of health workers, greater knowledge, development of tools, and higher priority;
- Improvement in national capacities, increased public awareness, and development of sustainable partnerships; and
- Reduction of the treatment gap, ensuring that more children with epilepsy attend school and that more adult epileptics work, along with other areas of social and economic impact.

WHO and its partners recognize epilepsy as an important public health problem. In an initiative launched in 1997, WHO, ILAE and IBE have been conducting the global “Out of the Shadows” campaign to provide better information and increase awareness about epilepsy, as well as to strengthen public and private efforts to improve care for the disease and reduce its impact. As with other such efforts, this epilepsy project has demonstrated that there are simple, cost-effective ways of treating the condition in settings where resources are scarce, and of significantly reducing the treatment gap. A project in China, for instance, resulted in a 13% reduction of the treatment gap in one year, with significant improvements in access to care for persons with epilepsy (28).

There are projects in many countries designed to reduce the treatment gap and morbidity associated with epilepsy, train and educate health professionals, eliminate the stigma associated with the disease, identify possible preventive strategies, and develop models to integrate the control of epilepsy in local health systems. In particular, the WHO program to reduce the treatment gap and mhGAP are currently seeking to achieve these objectives in Ghana, Mozambique, Myanmar, and Vietnam. The program combines various innovative strategies. It centers on integrating epilepsy care in primary health care, and increasing the abilities of non-specialized primary health care workers at the community level to diagnose, treat, and monitor persons with epilepsy. The results so far suggest that the treatment gap has been reduced by around 20%, and further indicate that, despite cultural differences and differences in health services, the project’s methodology has been effective and successful.

## **XII. Conclusions**

1. Epilepsy affects at least 50 million individuals worldwide, with 2.4 million new cases diagnosed each year globally.
2. Epilepsy is the most common chronic neurological disease and affects people of all ages, races, and social classes around the world.
3. Approximately 80% of persons with epilepsy live in low- and middle-income countries.

4. Epilepsy represents 0.5% of the total global disease burden and has important economic repercussions on health care and labor productivity.
5. Discrimination against persons with epilepsy creates difficulties for their education, employment, marriage, and social relations.
6. Persons with epilepsy often present with other conditions, such as depression and anxiety.
7. The risk of premature death in persons with epilepsy is up to three times higher than in the general population, with the highest rates found in low- and middle-income countries.
8. The majority of people with epilepsy could lead normal lives with proper treatment.
9. Approximately three fourths of epileptics in low- and middle-income countries do not receive the treatment they need.
10. Collaborative projects carried out by WHO have shown that training non-specialized primary health care workers at the community level to diagnose and treat epilepsy increases community awareness, and that identifying possible preventive strategies and developing models to integrate the control of epilepsy in local health care systems can be economically efficient and can successfully reduce the treatment gap.
11. Measures to reduce the problems and gaps associated with care for epilepsy are possible, but require collective involvement. The recent World Health Assembly resolution on the “Global burden of epilepsy and the need for coordinated action at the country level to address its health, social, and public knowledge implications” establishes a policy mandate and an opportunity to achieve these objectives.

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### III

## EPILEPSY IN LATIN AMERICA AND THE CARIBBEAN

### REPORT OF THE PAN AMERICAN HEALTH ORGANIZATION (2013)

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#### I. Introduction

In September 2011, the 51st Directing Council of PAHO adopted the Strategy and Plan of Action on Epilepsy (CD51/10) (1). Directing Council Resolution CD51.R8 (1) explicitly recognized the burden that epilepsy represents and the treatment gap that exists. It also reflects an understanding that this is “an important public health problem whose prevention, treatment, and rehabilitation are feasible through specific evidence-based measures.” It was therefore resolved to “endorse the provisions of the Strategy and Approve the Plan of Action on Epilepsy and their implementation under the particular conditions of each country.”

To a great extent, this Strategy is the result of much previous work to improve knowledge about epilepsy and its magnitude as a social and health problem. In 2008, in collaboration with ILAE and IBE, PAHO published the Report on Epilepsy in Latin America and the Caribbean (2), which, despite the limited sources of data available at that time, was an initial effort to shed light on the situation in the different countries.

This chapter is based on the most recent Report on Epilepsy in Latin America and the Caribbean, which was prepared by PAHO/WHO with support from ILAE and IBE, and published in 2013. It compiles the main data available on resources, programs, and services relevant to care for epileptics. It also presents epilepsy mortality information culled from WHO and PAHO databases.

This analysis provides a baseline, facilitating future measurement of many of the changes occurring in most of the Latin American and Caribbean nations. It can also help international organizations providing technical cooperation in the Region to identify problems, strengths, and priorities.

#### II. Report Methodology

A modified and adapted tool of the WHO Department of Mental Health and Substance Abuse (the Epilepsy Resource Assessment Tool) was used for data collection. This tool measures the availability of resources and services for individuals and groups with epilepsy, examining six categories of relevant factors: (1) health programs, legislation, and human rights; (2) leadership

and social participation; (3) cultural perceptions and traditional/alternative medicine; (4) services and technology; (5) human resources and training; and (6) information and research. Responses to the questionnaire were received in the second half of 2012.

The study included 25 countries, representing 76% of Latin America and Caribbean states and 97.4% of the region's total population. For analytical purposes, the countries were grouped into three subregions: the "Mexico, Central America, and Latin Caribbean" subregion (Costa Rica, Cuba, the Dominican Republic, El Salvador, Guatemala, Haiti, Honduras, Mexico, and Panama); the South American subregion (Argentina, Bolivia, Brazil, Chile, Colombia, Ecuador, Peru, Uruguay, and Venezuela); and the English-speaking Caribbean (Antigua and Barbuda, the Bahamas, Grenada, Jamaica, Saint Kitts and Nevis, Saint Vincent and the Grenadines, and Suriname).

The report has a number of limitations that should be borne in mind: (a) the government information comes from ministries of health, and in some cases the survey was answered by one or two key informants; (b) some items were not answered by some countries; (c) many questions simply ask informants to give their best estimate, or to answer "yes" or "no," which allows for a general appraisal, though it leaves more thorough analysis pending; and (d) the quality of data is not uniform across all countries.

Despite these limitations, however, this report is the most important and comprehensive effort, endorsed by the countries' governments, to compile information on epilepsy in the Region.

### **III. Analysis of findings**

#### **1. Health programs, legislation, and human rights**

It is essential for countries to have a plan or program for the care of epileptics if health care is to be organized consistently and comprehensively. Another essential element is legislation that is based on up-to-date knowledge of epilepsy and consistent with technical standards and human rights (1, 3).

The report indicates that only nine of the LAC countries surveyed (36%) – El Salvador, Guatemala, Mexico, Bolivia, Brazil, Chile, Colombia, Venezuela, and Bahamas – have a plan/program of action for the care of persons with epilepsy. Six of these countries have approved or updated their plans in the last 10 years (after 2002).

The legislative situation is even more critical: only 20% of the countries surveyed have national legislation relating to epilepsy. Of the five countries that do, only Chile, Colombia, and Venezuela have updated it since the end of 2002.

The presence of antiepileptic drugs (AEDs) on national lists of essential drugs is a vital element of the epilepsy program framework, of particular importance as a factor in the primary health

care system. According to the report, 92% of the countries' lists include phenobarbital, 92% phenytoin, 80% carbamazepine, and 72% valproic acid. Other AEDs are included on the essential drug lists for primary care in 33.3% of the countries. These include sodium valproate, diazepam, and clonazepam.

Persons with epilepsy are frequently subject to violations and restrictions of their human and civil rights in the form of unequal access to services, prejudicial treatment regarding health insurance and life insurance, restrictions on obtaining drivers' licenses, limitations on obtaining certain types of work, limited access to education, obstacles to entering into legal agreements and even, in some countries, constraints on marriage (2, 3). The report notes that 25% of the countries have limitations on obtaining or keeping jobs and 45.8% on obtaining drivers' licenses, while 20.8% have specific regulations/limitations relating to education.

Country reports revealed a lack of specific, reliable data on the proportion of government health budgets dedicated to care for epileptics. In future, this analysis should be strengthened, and the countries should be encouraged to implement mechanisms to better identify the structure of government spending.

## **2. Leadership and social participation**

Professional associations in the health field (principally in neurology) are an important component of efforts to improve the quality of care and the wellbeing of persons with epilepsy. Professional organizations can and should be involved in programs to educate the population and training and research, among other activities. There are organizations within the countries specifically dedicated to epilepsy, which generally function as national groups or chapters of ILAE and IBE.

The presence of user and/or family member groups is an important indicator of the degree of organization of a country's civil society, and of its potential for participating in planning and executing epilepsy-related programs. Person with epilepsy (users of health services) and their families are the stakeholders with the greatest interest in focusing attention on this health problem, and they should therefore be encouraged to organize and participate actively

Reports indicated the presence of 32 professional associations concerned with epilepsy, with 1,700 members distributed across 17 countries, while eight countries (32%) reported not having such organizations. There are 25 neurologists' associations, with 3,095 members, in 16 countries. Except for Jamaica, the English-speaking Caribbean countries lack professional associations related to care for epileptics, perhaps because these small island states have limited numbers of specialized human resources.

Reports indicated the existence of 45 user and/or family member groups, with a total of 1,151 members in 16 countries. However, the figure on number of members is clearly an



underestimate, since 56% of the countries indicated that this information was not available. Nine countries (36%) lack user and/or family member groups.

### **3. Cultural perceptions and traditional or alternative medicine**

It is essential to identify the myths and stigma surrounding epilepsy, as well as the current state of knowledge and existing attitudes. These factors serve as the basis for formulating community education plans, which are an important tool for the psychosocial rehabilitation of persons with epilepsy and for improving their living conditions.

In surveying key informants about the population's perceptions of epilepsy (general public, teachers, employers), 54.2% of the countries indicated that views of epilepsy have a discriminatory element, 70.8% noted that there is stigmatization, and 70.8% reported that epilepsy is regarded with fear. In terms of positive perceptions, only 29.2% stated that epilepsy is viewed with understanding, while 12.5% indicated empathy for the disorder.

With regard to the use of traditional or alternative medicine (use of shamans, in particular) to treat epilepsy, 68.2% of the countries report that the population frequently or occasionally uses these resources, while 31.8% report that such use is either nonexistent or infrequent. Thus, the data indicate that there is significant use of traditional or alternative healing for epilepsy in the population.

### **4. Services and technology**

Lack of access to services has been identified as the chief barrier to treatment for persons with epilepsy, especially in low- and middle-income countries. The main strategy for dealing with this problem is to improve the population's first line of contact with the health system. Training primary care workers to identify, manage, and (in complex cases) refer cases seems the most effective way of reducing the existing treatment gap.

Specialized out-patient and in-patient services (in neurology, epileptology, and neurosurgery, etc.) at the secondary care level are indispensable in supporting primary care and in dealing with complex cases that require specialized intervention. In many countries, these services are scarce, and are concentrated in the capital or in other large cities.

Reliable, ongoing availability of AEDs at the different levels of the health system is crucial for the success of national programs. PAHO's Regional Strategy urges governments to ensure that the primary care system has stocks of at least four essential AEDs: phenobarbital, carbamazepine, phenytoin, and valproic acid (1).

Epilepsy surgery is an important treatment option for persons with drug-resistant epilepsy. The Regional Strategy (1) recommends that a country have at least one center specializing in this procedure. For optimal case diagnosis and management, to deal with complications, and to

support the rehabilitation process, there is often a need for other services and disciplines, including psychiatry, neuropsychology, psychosocial rehabilitation, and special education.

Technology is necessary for the diagnosis and appropriate management of epilepsy. Today, most of the countries have electroencephalography (EEG), computerized axial tomography (CAT), and nuclear magnetic resonance imaging (NRM). The problem lies in the inequitable geographical distribution of these resources: they are concentrated in capitals and other large cities, and in some cases in expensive private facilities.

The countries reported 342 specialized centers or services providing care for epileptics in 20 countries. Two countries (Brazil and Saint Kitts and Nevis) did not provide information on this question. Of the countries that responded, only three (all in the English-speaking Caribbean) lack this type of service. South America is the subregion with the greatest number (208) of these specialized facilities.

The countries show an unequal distribution of services, with high, or even total, concentration in the capital cities, where approximately one third (36%) of specialized facilities and services are located.

There are 97 facilities (28.4% of the total) distributed across 16 countries that have specialized (neurology or epilepsy-specific) centers or services dedicated exclusively or partially to epileptic children and adolescents.

There are 94 surgical facilities for epilepsy treatment in 16 countries (64%), while nine countries (36%) lack such facilities. The English-speaking Caribbean has no such facilities, while South America has the greatest number (76).

The total number of individuals operated on annually is highest in South America, with 258 cases per year. Mexico, Central America, and the Latin Caribbean report only 35 cases, while the English-speaking Caribbean reports none. These figures are underestimates, since several countries with surgical services for epilepsy (Cuba, Mexico, Bolivia, Brazil, and Peru) did not provide information on the number of surgeries carried out. Leaving aside Brazil (which did not report on the territorial distribution of surgical facilities), two thirds of these facilities are in national capitals.

Of the countries that provided information, 95.2% have AEDs available (at least one year-round) in hospitals, 76.2% in out-patient facilities, and 61.9% at the primary care level. The reports did not clarify whether this availability applies throughout the national territory, and four countries provided no information on AED availability.

In 84% of the countries, electroencephalography (EEG) is available, 88.0% have computerized axial tomography (CAT), and 76% have nuclear magnetic resonance imaging (NMR) (Figure 5). This does not mean that these technologies provide complete coverage of the needs of persons

with epilepsy. The scarcest technologies are single-photon emission computed tomography (SPECT) and positron emission tomography (PET).

In 84% of the countries, primary care doctors are authorized to diagnose epilepsy and begin treatment. In the remaining countries, initial diagnosis and the initiation of treatment must be performed by a specialist.

A full 95.8% of the countries have formal, institutionalized systems or mechanisms for the referral and counter-referral of persons with epilepsy for diagnostic and/or treatment purposes.

For many epilepsy sufferers, optimal diagnosis, treatment, and rehabilitation often require other, supplementary, associated or specialized services. All countries that reported on such offerings have psychiatric services available, while 79.2% have rehabilitation services, 70.8% have neuropsychological services, and 42.9% provide special services for children and/or adolescents.

According to a qualitative analysis of the countries, the main problems affecting the care of epileptics include the following: 66.7% of the countries cite problems in diagnosing cases; 62.5% note delays in providing care; 29.2% report patient dissatisfaction; and 33.3% report limitations or lack of access to facilities capable of providing proper care for individuals with epilepsy.

## **5. Human resources and training**

The report evaluates the number of available health professionals fully or partially dedicated to epilepsy care—an essential component of epilepsy-related facilities and programs, including programs to train primary care personnel. A crucial element of graduate-level education is the availability of regular, systematic programs that provide training on epilepsy for primary care physicians. These programs should be linked to actual practice and to support/supervisory mechanisms, in order to improve the response capacity of primary care systems.

Four English-speaking Caribbean countries have no neurologists, and three South American countries (Argentina, Brazil, and Peru) failed to provide information on this question. The remaining 18 countries report having 3,587 neurologists, representing a regional average of 1.18 per 100,000 inhabitants. These neurologists are highly concentrated in the countries' capital cities.

The number of neurologists per 100,000 inhabitants varies widely from country to country. The highest levels for this indicator are in Cuba (3.66), Ecuador (3.53), Uruguay (3.45), Chile (3.27), and Venezuela (1.69). The remaining countries have less than one neurologist per 100,000 inhabitants.

A total of 935 neurologists was reported among 15 countries. Six countries did not answer this question, and four have no neurologists. South America has the greatest number of these specialists. The English-speaking Caribbean has only five pediatric neurologists.

A total of 2,553 neurosurgeons was reported in 19 countries, for a regional average of 0.78 per 100,000 inhabitants. Three South American countries did not report on this, while three countries in the English-speaking Caribbean reported having no such specialists. In terms of rates per 100,000 inhabitants, the best equipped countries are Cuba (1.91), Venezuela (1.35), and Uruguay (1.03). The remaining countries in LAC have less than one neurosurgeon per 100,000 inhabitants.

The report shows that 341 physicians (in 12 countries) are currently in neurology residencies. Nine countries have no residency programs in this specialty: Panama, Antigua and Barbuda, the Bahamas, El Salvador, Granada, Haiti, Saint Kitts and Nevis, Saint Vincent and the Grenadines, and Suriname. Four countries did not report on this question.

Twelve countries reported having a total of 233 epileptologists, six countries reported having none, and seven countries did not answer the question.

There are continuing medical education/training programs in epilepsy in 60.9% of the countries; 54.5% of the countries have scientific associations that offer courses or programs for skills enhancement or training; at least some public hospitals in 36.4% of the countries offer programs of this type; and in 13.6% of the countries, such programs are in place in private hospitals. In 18.2% of the countries, NGOs provide continuing medical education. Two countries (Costa Rica and Suriname) failed to provide this information, and Brazil did not specify which institutions provide training/continuing medical education.

Only eight countries (33.3%) of those that reported information on this subject stated that they have regular training programs for primary care professionals: Bahamas, Colombia, El Salvador, Guatemala, Honduras, Jamaica, Mexico, and Panama. In no case do these programs cover the entire national primary care network.

## **6. Information and research**

A good information system at the ministries of health is essential for correct situation analysis, and for providing data that can serve as a basis for planning. In the case of epilepsy, health information systems must define and incorporate a minimum set of data and indicators.

Countries with access to studies and research data will be in a better position to conduct advocacy on the issue and to establish priorities, examine trends, and evaluate the impact of interventions.

It was reported that 64% of the countries have basic data (minimum information) on epilepsy, compiled by the respective ministries of health, while 40% possess epidemiological studies. In 24% of the countries, there are reports or studies on care services for epileptics, and 24% have studies on the quality of care provided.

## **II. Mortality**

In the Region of the Americas, there is an annual average of 7,547 deaths (1,676 in North America and 5,871 in LAC) for which epilepsy is the primary cause. Disaggregated by sex, men account for 62.1% of deaths due to epilepsy in LAC.

The regional epilepsy mortality rate is 0.84 per 100,000 inhabitants: 0.50 per 100,000 in North America and 1.04 per 100,000 in LAC. The male mortality rate in LAC is 1.27 per 100,000, while the female mortality rate is 0.80 per 100,000. Analysis by age group shows higher mortality among older adults (2.28 per 100,000 for both sexes in LAC).

## **III. Final considerations**

In 2013, PAHO, with support from ILAE and IBE, published a report on resources, programs, and services related to epilepsy care in Latin America and the Caribbean, which is the basis for the present article. The most important points covered by the report include the following:

1. Approximately two thirds of the countries have no program or plan of action in the health sector for epilepsy care.
2. About 80% of LAC countries have no legislation relating to epilepsy, and discriminatory legal regulations persist.
3. Organizations that bring together users and families do not have a strong presence in the Region, and 36% of the countries surveyed have no such organizations.
4. As a disease, epilepsy continues to be perceived by the population in a discriminatory and stigmatizing manner.
5. In 87% of the countries, there are specialized facilities for epilepsy, or neurological facilities that deal with epilepsy. There are 94 surgical facilities for epilepsy cases in 16 of the 25 countries covered in the report.
6. Though the four basic antiepileptic drugs are included on almost all of the countries' national lists of essential drugs, they are not always available throughout the national territories. Only 62% of the countries reported that AEDs are available year-round in the primary care system.
7. The countries reported difficulties in diagnosis, and delays in providing care, as the most common major problems.
8. Rates of 1.18 neurologists per 100,000 inhabitants and 0.78 neurosurgeons per 100,000 inhabitants were reported. Twelve LAC countries reported having physicians with special training in epilepsy. There are 341 doctors doing residencies in neurology in 12 countries.

9. One decisive element is the unequal or inequitable distribution of epilepsy-related facilities and human and technological resources. In some countries, the coverage that the public sector is able to provide is limited, while private services are so costly as to be inaccessible for the majority of the population.
10. Only one third of the countries reported having a regular program for continuing medical education/training in epilepsy for medical professionals in the primary care system. The capacity of the primary care system to deal effectively with epilepsy needs to be improved to ensure early diagnosis and appropriate case management. This is an essential element of efforts to reduce the treatment gap.
11. One third of the countries' national health information systems lack basic data on epilepsy.
12. Latin America and the Caribbean have an annual average of 5,870 deaths due to epilepsy, or 1.04 deaths per 100,000 inhabitants.

#### **IV. Supplementary section. ATLAS: Country resources for neurological disorders / 2014 questionnaire. Preliminary analysis for the Region of the Americas<sup>1</sup>**

In 2004, WHO, in collaboration with the World Federation of Neurology, produced its “Atlas” of resources for neurological disorders.<sup>2</sup> The Atlas is a tool widely used at the global level to obtain information on neurology, and it is an important resource for development and planning at health services in many countries. The WHO Department of Mental Health and Substance Abuse and the World Federation of Neurology are currently working on a new version of the Atlas, which will provide more extensive information on current resources in the field of neurology than did the previous edition.

Project Atlas (country resources for neurological disorders—2015) brings together data from ministries of health and national neurological associations, in order to provide the broadest and most comprehensive picture possible of the resources that are available to care for people with neurological disorders. These two sources provide complementary information.

Neurological disorders covered in this study include: dementia, epilepsy, cephalaeas, cerebrovascular diseases, neurological developmental disorders, Parkinson’s disease, multiple sclerosis, infections of the nervous system, and traumatic brain injuries.

Epilepsy is one of the most common neurological disorders. Thus, an important component of the countries’ neurological services and resources are dedicated to caring for sufferers of this disease. A study of this type is therefore vital for analyzing health systems’ response to the problem of neurological disorders, including epilepsy.

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<sup>1</sup> The data analyzed in this section are preliminary and are subject to variations in the final WHO Atlas-2015 version.

<sup>2</sup> [http://www.who.int/mental\\_health/neurology/epidemiology/en/](http://www.who.int/mental_health/neurology/epidemiology/en/)

In the Region of the Americas, 24 countries<sup>3</sup> responded to the WHO Atlas questionnaire on neurological disorders. Thus, all of the data analyzed here are based on that group of countries. The present analysis draws on responses to the questionnaires that the Region's countries provided to WHO.

Some sections from the Atlas were selected for this technical document, particularly those directly related to epilepsy. They are briefly described below.

### **Inclusion of neurological disorders in health policies or plans, and in legislation**

One third of the countries do not include neurological disorders in their national health policies or plans. In terms of the remaining countries: 54% take them into account in their national health policies and 54% incorporate them in their national mental health plans, but only 17% have a national plan or program dedicated to neurological disorders. According to the information reported, epilepsy is covered specifically in the legislation of only six countries (25%).

### **Social protections**

Only four countries in the Region (17%) reported that they have no type of program providing support or social protection to persons with neurological disorders, specifically those with major disabilities. Financial support programs exist in 17 countries (71%); 11 countries (46%) have non-financial social support programs; and only 10 countries (42%) have residential services or programs.

### **Number of neurologists per 100,000 inhabitants**

Two countries failed to report this information, and over half of the countries (54%) have less than one neurologist per 100,000 inhabitants. In 17% of the countries this figure is between one and two per 100,000 inhabitants, while only five countries (21%) reported more than 2 neurologists per 100,000 inhabitants.

### **Neurology beds**

Ten countries did not report or stated that they did not have this information. Five countries (21%) have no neurology beds; 38% have beds, but only four (17%) have more than one bed per 100,000 inhabitants.

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<sup>3</sup> Barbados, Belize, Bolivia, Brazil, Canada, Chile, Colombia, Costa Rica, Dominican Republic, Ecuador, El Salvador, Guatemala, Guyana, Haiti, Honduras, Mexico, Nicaragua, Panama, Peru, Puerto Rico, Saint Martin, Suriname, United States, and Uruguay.

### **Hospital neurology units for epilepsy surgery**

Fourteen countries (59%) have one or more neurology units/services; only 9 countries (38%) have units/services specializing in epilepsy surgery.

### **Clinical guidelines for neurological disorders**

Fourteen countries (58%) have clinical guidelines for neurological disorders, in most cases directed at primary care settings. The extent to which they are implemented is not specified.

### **Information systems**

Thirteen countries (54%) have data on neurological disorders incorporated in their regular health information systems. Ten countries (42%) include some data on epilepsy in the annual reports of their national health information systems. In 11 countries (46%), epilepsy is covered in data that is collected regarding the use of health services.

## **FINAL CONSIDERATIONS**

For the care of persons with epilepsy, it is essential to strengthen neurological programs and services, since they provide the foundation for specialized secondary and tertiary care. It is also important to provide support at the primary care level, in order to improve the capacity for handling cases effectively at that level. Epilepsy is one of the disorders most frequently presenting at facilities that offer neurological services.

Despite the efforts of the WHO Atlas project, a large number of countries did not respond to the questionnaire, and the data gathered are in some cases inconsistent. Despite these weaknesses, the report provides valuable information identifying problems and priorities. The following points are particularly significant:

- Neurological disorders need to be incorporated in national health policies and plans and assigned priority importance. The legislative situation is critical: only six of the Region's countries report having legal instruments in the area of neurology.
- Programs providing social protection or support for persons with neurological disorders are present in 83% of the countries, and focus specifically on individuals with major disabilities. This is a positive sign, though deeper analysis is needed regarding types of programs, responsiveness to needs, and coverage.
- In many countries, specialized human and institutional resources are limited and scarce, in addition to being concentrated in capitals and other large cities. The development and strengthening of human resources continues to be a priority.



- It is vital to incorporate clinical guidelines on the neurological disorders that present most frequently in primary care. This should be an ongoing process, and requires supervision and support. The information reported (58% of the countries have clinical guidelines for the primary care level) indicates progress, which should be monitored and strengthened
- Information on neurological disorders and epilepsy is still very limited in national health systems. Around half of the countries do not cover these conditions when collecting data and conducting analyses.

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## IV

# CARE FOR PEOPLE WITH EPILEPSY IN CHILE: NATIONAL EPILEPSY PROGRAM

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### I. Introduction

The purpose of this chapter is to describe improvements that have been made in Chile for the care of people with epilepsy. The Chilean League Against Epilepsy and the Epileptology Society of Chile were features of the country's landscape in 2000, and the latter organization worked with the Ministry of Health to design and implement a National Plan for Epilepsy (1).

The professional group involved in these efforts included experts in child and adult neurology, a psychiatrist, a nurse, and a social worker. This group, with support from the Quality Unit of the Public Health Department at the Ministry of Health, headed at the time by Dr. Gilda Gnecco Tassara, conducted the 2001 National Epilepsy Survey, which revealed important structural deficiencies and problems in the provision of health services to people with epilepsy.

As a follow-up to that work, the Ministry of Public Health issued four policy documents, including technical and administrative standards for epilepsy care, paving the way for a better standard of care for this disorder (2, 3, 4) ([www.redcronicas.cl](http://www.redcronicas.cl)).

In 2004, within the framework of the country's Health System Reform, and Supreme Decree No. 170 of November 2004, Law No. 19.996, which defined a "General Regime of Explicit Health Guarantees," was passed. This law establishes and regulates the provision of state resources for health services, and includes guarantees with respect to access, quality, financial insurance, and timeliness of care ([www.minsal.cl](http://www.minsal.cl)).

With the new revelations concerning the country's existing care gap, and with improved standards in place, non-refractory epilepsy (epilepsy unresponsive to drugs) became a covered chronic disorder under the Universal Plan of Health Guarantees (GES) in 2005, ranking among the 25 highest-priority pathologies. This priority list has expanded over time and now includes 80 diseases. Childhood epilepsy was initially included, with adult epilepsy being added subsequently (5).

From its inception, the GES plan addressed the need for increased investment. It created new positions for neurologists in nine of the country's regions, and 25 pieces of state-of-the-art digital electroencephalography equipment were purchased, as well as laboratory equipment for the analysis of plasma drug levels. The National Health Fund Basket (Canasta Fondo Nacional en

Salud), which provides government funds for public hospitals and primary care facilities, as well as for private care facilities, was modified to include epilepsy-related resources, based on the number of epileptics receiving care.

Between 2005 and December 2013, a total of 7,437 child and 23,462 adult non-refractory epilepsy sufferers joined the GES plan as part of the FONASA group (FONASA, the National Health Fund, provides public funding for individual health care), making a total of 30,899 persons. Many of these, however, withdrew during that period, leaving 7,531 receiving GES benefits as of December 2013. These data cannot be interpreted as measures of the national prevalence or incidence of epilepsy, since they do not reflect information on patients in the private health care system who are also GES beneficiaries. Moreover, not all FONASA beneficiaries make use of the guarantees, for reasons that are currently under study.

## II. Description of individual health care for epilepsy as part of the Universal Plan of Explicit Health Guarantees (GES)

GES provides benefits for all Chileans affiliated with public or private health care providers. It guarantees access, timely care, financial protection, and care quality.

The **guarantee of access** stipulates that any child with epilepsy, between the ages of 1 and 15 years old, may enter the system as soon as epilepsy is suspected. Persons over 15 may enter the system once a diagnosis of non-refractory epilepsy (epilepsy that is unresponsive to drugs) is made. After being admitted, the child is covered by the **guarantee of timeliness**, with a maximum timeframe (60 days) for receiving care by a neurologist at the medium level of complexity, and another timeframe (seven days) for the provision of drugs at the low-complexity level. If a child does not receive the required care within the established timeframes, a complaint can be lodged with the provider responsible for the child's care. It can also happen that the child's family (or the adult patient) does not desire treatment through GES, in which case a written document can be submitted declining treatment. Only a neurologist can diagnose or discharge the patient, regardless of whether the patient is a child or an adult.

The **financial protection guarantee** sets copayments for GES beneficiaries that vary according to the patient's type of plan membership. For those affiliated with FONASA who are in groups A and B (the most socioeconomically vulnerable groups), service is free. For those in group C, the per-patient copay is 10%, and for those in group D, 20%. The same formula applies to subscribers in private-provider plans.

Since 2013, the quality **guarantee requires** care to be provided by professionals registered with the Superintendency of Health, and beginning in 2016 when the guarantees enters into effect for high-complexity facilities, these facilities must be accredited and registered.

The **guarantees for children between the ages of 1 and 15 with epilepsy** are as follows:

Stage	Guarantees/Guaranteed tests
1. Initial stage at secondary/medium-complexity level	<ul style="list-style-type: none"> <li>- Seen monthly by neurologist</li> <li>- Seen monthly by nurse</li> <li>- Complete hemogram and erythrocyte sedimentation rate (ESR)</li> <li>- TSH (thyroid-stimulating hormone) and T4 analysis</li> <li>- Glycemia, calcemia, phosphemia, blood gas, and pH balance</li> <li>- Blood creatinine and plasma electrolytes</li> <li>- Sleep-deprived EEG</li> <li>- Measurement of plasma drug levels</li> <li>- Drugs provided: valproic acid (drops, syrup, and tablets), carbamazepine (tablets), clonazepam (tablets), lamotrigine (tablets), levetiracetam (tablets and syrup), phenytoin and phenobarbital (tablets)</li> </ul>
2. First year of treatment at primary/low-complexity level	<ul style="list-style-type: none"> <li>- Full medical exam</li> <li>- Exam by nurse</li> <li>- Exam by clinical psychologist</li> <li>- Home visit by social worker</li> <li>- Liver function panel</li> <li>- Same drugs as in the diagnostic phase plus folic acid</li> </ul>
3. First year of treatment at secondary/medium-complexity level	<ul style="list-style-type: none"> <li>- Seen annually by neurologist</li> <li>- Seen annually by nurse</li> <li>- Complete hemogram and ESR</li> <li>- Liver function panel</li> <li>- EEG</li> <li>- Measurement of plasma drug levels</li> <li>- Same drugs</li> </ul>
4. Exams and treatment starting year two at primary/low-complexity level	<ul style="list-style-type: none"> <li>- Full medical exam</li> <li>- Exam by nurse</li> <li>- Same drugs</li> </ul>
5. Exams and treatment starting year two at secondary/medium-complexity level	<ul style="list-style-type: none"> <li>- Exam by neurologist</li> <li>- Exam by nurse</li> <li>- Same drugs</li> <li>- EEG</li> </ul>
6. Final stage: Discharge	The neurologist assesses discharge after six months of monitoring without drugs

The **guarantees for non-refractory epilepsy in adults** (ages 15+) consist of:

1. Admission to GES, once non-refractory epilepsy is diagnosed (at the treatment stage)
2. Treatment stage starting in year one at the primary/low-complexity level:
  - Full medical exam
  - Exam by nurse
  - Liver function panel
  - Drugs: valproic acid (regular and slow-release tablets), carbamazepine (regular and time-release tablets), clonazepam tablets, lamotrigine tablets, levetiracetam tablets, phenytoin, phenobarbital, and folic acid.
3. Treatment stage starting in year one at the secondary/medium-complexity level:
  - Annual exam by neurologist
  - Annual EEG
  - Complete hemogram with ESR, plasma electrolytes
  - TSH and T4 analysis
  - Liver function panel
  - Plasma drug levels
  - Same drugs as in primary care

**Clinical Practice Guidelines (CPGs) for epilepsy (5):** Since epilepsy care became part of GES, the Ministry of Health has published three official versions of the child CPGs (2005, 2008, and 2014), and two versions of the adult CPGs (2007 and 2014) ([www.minsal.cl](http://www.minsal.cl) and [www.redcronicas.cl](http://www.redcronicas.cl)).

Fifty professionals in the public and private health systems with experience in the field of epilepsy participated in the 2014 update of the guidelines. The new guidelines incorporate chapters on diagnosis, medical and surgical treatment, education, epilepsy in newborns, psychiatry, management of epileptic states, quality of life, etc.

**The Continuing Education Program on Epilepsy:** In 2014, the Ministry of Health planned an online program for education on epilepsy directed at primary care professionals, covering both epilepsy issues and optimal use of GES resources.

Over the course of 2015, the Ministry of Health has been revising and expanding the epilepsy program. This includes incorporating benefits for persons suffering from refractory epilepsy, with multi-disciplinary care, and enhanced care at the more complex levels, such as epileptic surgery, ketogenic diet, etc. This program is based on a calculation of 6,300 new cases of epilepsy annually and an estimated prevalence of 122,302 persons (National Institute of Statistics).

To justify this expansion of the National Epilepsy Program, a cost effectiveness study was conducted by the Health Ministry's Department of Health Economics. The study was published in 2011 as an internal ministerial document. It describes the cases of 4,819 adults with epilepsy, selected from different regions in order to make the findings representative of the Chilean population. The study analyzed both direct and indirect costs.

The study revealed a gap of 1.398 between efficacy and effectiveness, measured in terms of

Intervention	Efficacy: DALY prevented per case treated	Effectiveness: DALY prevented per case treated	Gap between efficacy and effectiveness in terms of DALY
Treatment of epilepsy in adults	0.8903	0.6002	1.3982

DALY (disability-adjusted life years) (see table below), showing that epilepsy interventions, primarily to ensure adherence to treatment, can be a very cost effective way of improving the quality of life of sufferers (6).

In 2007, the Chilean League Against Epilepsy conducted a study of direct costs in a group of epileptics receiving care at that institution’s medical center. Six groups of individuals were analyzed (recently diagnosed, crisis in remission, occasional seizures, active and not drug-resistant, drug-resistant, surgery cases), for a total of 293 individuals. The findings showed that the highest expenditure was on medications (81.1%), followed by neurological consultations, laboratory work, and neuroradiology. Surgery cases constituted the group with the greatest annual cost, followed by the group of AED-refractory patients. Since there was no follow-up to the study, there is no way of knowing whether the medium-/short-range costs in the group undergoing surgery declined, or the relation between costs and recovery. Averaging across all groups, the annual per-case cost was US\$615, mid-way between the cost in developed and in developing countries (7).

Analyzing the available information on epilepsy, it was estimated that despite the GES plan, there is still a very significant care gap in Chile for persons with epilepsy. This suggested a need to reconfigure the National Epilepsy Program, in order to create greater systematization and incorporate greater benefits. The aim is to improve the quality of life of epilepsy sufferers and their families using new strategies, such as: stratifying epilepsy care in five levels, as opposed to the current three; creating a Model Experimental Center; developing teaching plans for specialists; providing ongoing training on epilepsy for primary care professionals; and providing multi-disciplinary care; etc. The new program was expected to be in place by January 2016.

### III. Conclusions

1. Chile has had a National Epilepsy Plan since 2002 and is one of the most advanced countries in Latin America in the field.
2. The Universal Plan of Explicit Health Guarantees (GES) provides benefits for all Chileans affiliated with public or private health care providers. It includes guarantees of access, timely care, financial protection, and care quality.

3. Epilepsy (non-refractory) became part of GES in 2005 as one of the 25 highest-priority pathologies in Chile.
4. The guarantee of access allows children with epilepsy to enter the system at the stage where epilepsy is suspected. Adults can enter the system once a diagnosis of non-refractory epilepsy is made.
5. The timeliness guarantee defines the timeframes for receiving neurological care, and for the provision of medications at the low-complexity level.
6. The financial protection guarantee defines copayments for GES beneficiaries, varying according to type of membership in the plan. For those affiliated with the National Health Plan (FONASA) who fall in socioeconomic groups A and B (the most vulnerable), services are free.
7. The quality guarantee states that, starting in 2015, all providers must be accredited to provide care related to pathologies included in the GES.
8. A new Epilepsy Program is currently being created. It will expand benefits and organize care in five levels, according to specified criteria.

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## CLINICAL PRACTICE GUIDELINES FOR EPILEPSY: THE CHILEAN EXPERIENCE

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### I. Introduction

The purpose of this chapter is to briefly describe Chile's experience in developing clinical guidelines as part of the National Policy and Plan on Epilepsy of the Ministry of Health (MINSAL), which has been in place since 2000, in collaboration with a very active technical group composed of representatives of different sectors, including MINSAL, scientific associations, and non-governmental organizations (NGOs) (1).

Over the years, several guidelines and technical standards have been developed (2, 3, 4), and scientific associations and NGOs have focused on producing other technical documents to improve the use of drugs. Participating in this process have been: the National Association of Leagues Against Epilepsy (ANLICHE), which is an IBE chapter in Chile; the Chilean League Against Epilepsy (LICHE); the Epileptology Society of Chile, which is the Chilean chapter of ILAE; the Society of Childhood and Adolescent Psychiatry and Neurology (SOPNIA); and the Neurology, Psychiatry and Neurosurgery Society (SONEPSYN). Some organizations of parents or friends of patients with epilepsy have also participated. All of these entities have played an active role in designing and implementing the National Epilepsy Plan.

Three types of normative technical documents have been issued in Chile:

- **Clinical Practice Guidelines:** Recommendations designed to support decision-making for health professionals and patients on health care appropriate to specific clinical circumstances, in light of the best available scientific evidence found through a systematic review of the literature.
- **Technical health standards:** This document defines one or more mandatory actions, with compliance regulated under a resolution of the Legal Department of the Ministry of Health, or under a law or other valid administrative instrument. It refers directly to promotion, prevention, diagnosis, therapy, and rehabilitation, as related to a health problem.
- **Protocols:** These are instructions of a referential nature on the operational management of certain health problems. The protocols will be mandatory only if and when a resolution is adopted in response to a health need that requires it.



## II. Clinical Practice Guidelines

This chapter deals with Clinical Practice Guidelines. Through the years in Chile, various clinical guidelines have been developed and implemented, including the Childhood Neuropsychiatry Guide, in 1980 (5); the Clinical Guides for Epilepsy, in 1990 (6); the AUGE Guide on Epilepsy in Children, in 2005 (7); the subsequent 2008 Guide on Epilepsy in Children (8); the 2010 Guide on Epilepsy in Adults (9); and the Chilean Consensus on Use of Antiepileptic Drugs (AEDs), in 2011 (10).

The epilepsy guides of Chile's Ministry of Health were updated and published in late 2014, and now include additional material on education, learning, psychiatric comorbidity, and quality of life, among other topics (11, 12). The objectives of the clinical guidelines on epilepsy are:

1. To provide guidance for general practitioners and specialists, as well as for other health professionals, on the management of epilepsy in children and adults, with a focus on diagnosis and treatment.
2. To optimize the use of resources available in the health system.
3. To ensure quality care for persons with epilepsy.
4. To improve the efficiency of the care network.

One particularly important undertaking in Chile was the process that produced the document known as the Chilean Consensus on the Management of Antiepileptic Drugs. The purpose of this joint initiative by LICHE, SONIA, and the Epileptology Society of Chile was to create uniform criteria for the prescription of AEDs, since, according to data from a survey, a wide range of different criteria were being employed, even by specialists (13). Various factors were considered in developing the consensus document, some of the most important being that: (a) epilepsy cases are heterogeneous, and exhibit a variety of characteristics, with different treatments and prognoses; (b) trends in pharmacological treatment have changed rapidly with new formulations of the traditional AEDs and the advent of new drugs; and (c) the numerous clinical studies, presenting new evidence, can complicate professionals' treatment decisions.

Almost all pediatric neurologists in Chile participated in developing the consensus document, and the exercise showed how difficult and complex this normative task is. It requires reviewing the evidence available in the literature, and then determining how to apply it to the realities of the Region's countries. The exercise was also costly.

This collective effort to produce clinical guidelines, in coordination with health sector authorities, is necessary and should be carried out at least once at the country level, with subsequent efforts aimed at expanding and updating the guidelines every three to five years, as part of a national epilepsy program.

The Chilean Consensus is an excellent example, and highlights important lessons. It was initially developed merely as a set of recommendations, but subsequent evaluation – including a survey (written and virtual) – confirmed its utility (14).

Currently, the Clinical Guides on Epilepsy and the Consensus document are used to support clinical practice, where their value for decision-making is well recognized. In addition, they establish consistent criteria for appropriate and optimal use of AEDs, based on the best available scientific evidence. They are also useful as teaching materials, and contribute to the implementation of epilepsy programs. A document on the use of the AEDs in adult epileptic seizures, developed by SONEPSYN and LICHE, has also been made available (15).

### III. Conclusions and Recommendations

1. In the framework of a national epilepsy program, Clinical Practice Guidelines are an essential tool. There should be a concerted effort to revise and update them, ideally every three to five years.
2. The guidelines should be developed by working groups whose members have sufficient experience with the subject, and who represent different institutions (ministry of health, scientific associations, and NGOs). The collaboration of various institutions and the use of virtual communications can improve quality, ensure consensus, and reduce the cost of preparing these technical documents.
3. Clinical Practice Guidelines provide guidance and direction for physicians from the primary care level to the tertiary level.
4. Such normative technical documents are frequently produced by different health service providers, creating a risk that the protocols that are developed will be of low quality or incomplete. It is therefore recommended that these guides be national, and that they be consistent with the national epilepsy program, so that they can be used by all of the country's health care providers.
5. International consensus on the use of antiepileptic drugs – based on scientific evidence – is highly useful, but must be adapted to the realities of the individual countries.

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## EPILEPSY EPIDEMIOLOGY IN HONDURAS

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### I. Introduction

Epidemiological research on epilepsy is crucial to understanding its causes, prevention, management, and other related factors (1). Epidemiological studies of epilepsy began in Honduras in 1997, with the support of the graduate program in neurology at the School of Medical Sciences of the National Autonomous University of Honduras. Genetic studies have identified the EFCH1 gene in juvenile myoclonic epilepsy and the GABRB3 gene in absence seizure epilepsy in children (2, 3).

These research initiatives were undertaken as part of the global focus on epilepsy, their purpose being to determine the magnitude of the problem and the treatment gap in Honduras. They are also aimed at developing an effective primary-care intervention strategy (1). The studies referred to in this chapter are the following:

- National epidemiological study on epilepsy in Honduras (1999-2000) (4).
- Epidemiological studies on epilepsy in a rural area in Honduras: the Salamá study and its monitoring over 17 years (1996-1997, 2005, 2014) (5-7).
- Epidemiological studies of neurological diseases and epilepsy in an urban area of Honduras (2001) (8, 9).

### II. Findings of epidemiological research

#### Determination of the prevalence and incidence of epilepsy

Epilepsy affects approximately 50 million people worldwide at some time in their lives, but especially in childhood and adolescence. It is a universal problem, affecting people of all ages, races, social classes, and nations (1); 80% of persons with epilepsy live in developing countries.

Burneo et al. (10) conducted a systematic review of 33 community-based studies on the prevalence and incidence of epilepsy in Latin America, and report an average annual lifetime prevalence for the Region of 17.8 (range 6.0-43.2) per 1,000 inhabitants, and a range of incidence of 77.7-190 per 100,000 inhabitants (10).

A national epidemiological evaluation of epilepsy in Honduras based on a sample of 135,035 inhabitants produced findings not far from the regional ranges, and although national prevalence was low (6.63 per 1,000 inhabitants, with a range of 1.0-23.3/1,000), the incidence was 104 per 100,000. The departments with the highest prevalence rates were, in descending order, Olancho (9.23/1,000), Santa Bárbara (9.17/1,000), and Francisco Morazán (8.52/1,000) (Figure 1). The lowest prevalences were in Islas de la Bahía (2.24/1,000) and Gracias a Dios (2.70/1,000). However, when rates are analyzed at the municipal level, much higher rates appear: 23.3/1,000 in Salamá, in the department of Olancho; 20.3 and 20/1,000 in El Triunfo and Morolica, respectively, in the department of Choluteca; 19.2/1,000 in Curarén, in the department of Francisco Morazán; and 15.7/1,000 in Colinas, in the department of Santa Bárbara (Figure 2) (4). These differences are probably attributable to the genetic, health, and socioeconomic conditions of those municipalities.

The first neuroepidemiological studies conducted in specific rural and urban areas in Honduras were the “Salamá” rural study (1996-1997) and the “Kennedy” study (Tegucigalpa, 2001). The Salamá study measured the incidence, prevalence, and etiology of epilepsy in a rural area. The prevalence of active epilepsy was 15.4/1,000, with an incidence of 92.7/100,000. The etiology of the active cases of epilepsy studied mostly involved neurocysticercosis (NCC) (37%), perinatal brain injury (8%), post-traumatic injury (3%), and sequelae of cerebrovascular disease (2%); 8% were idiopathic and 30% cryptogenic. The study showed that epilepsy was more frequent in the under-25 age group (Table 1) (5). The Kennedy study in Tegucigalpa showed prevalence of 7.2/1,000 inhabitants, suggesting that the high prevalence of epilepsy in Honduras is related to socioeconomic and health conditions (8). This situation is not unlike that of other developing countries, where there are regional differences within individual countries, with lower prevalence and incidence of epilepsy in places where socioeconomic development indicators are better (11).

Although case-control studies have not been conducted, the various studies carried out in Honduras show the most frequent antecedents of epilepsy to be: family history of epilepsy (24%) (4); perinatal brain injury (6.6%-11.11%) (5, 6, 9); birth outside of hospital settings (27%) (4); cranial trauma (3%-13.3%) (5, 6, 9); febrile seizures (10.5%) (5); sequelae of cerebrovascular disease (2%-13.3%) (5, 6, 9); cortical dysplasia (5.6%); meningitis/encephalitis (2.8%) (6); and NCC (13.9%-37%) (5, 6, 9).

### **Reduction in the incidence of epilepsy**

The community of Salamá was the focus of a population study to assess the impact of a community-based epilepsy reduction intervention program initiated in 1997, after eight years

of implementation (1998-2005). The study showed reduced incidence in the final four years (2002-2005), with the incidence of active epilepsy dropping from 118/100,000 to 35.7/100,000 and an average annual incidence during the period of 75.2/100,000 (Table 2) (6).

Another study, conducted in 1996 and 1997, found that in nearly 37% of the patients with active epilepsy who were studied, the disease was caused by NCC, and that this percentage dropped significantly (to 5/36 cases, or 13.9%) between 1998 and 2005 ( $p=0.02$ ) (Table 3). It is estimated that around 11 new cases of epilepsy caused by NCC were prevented by the various interventions conducted (community education, creation of infrastructure for the proper elimination of excrement, water treatment, etc.) (6). These results were achieved thanks to the joint work of Honduras's Secretariat of Health, the municipality of Salamá, the graduate neurology program at the School of Medical Sciences of the National Autonomous University of Honduras (UNAH), and the World Bank.

### **The epilepsy treatment gap**

A systematic review of the epilepsy treatment gap conducted by Meyer et al. (12) shows a dramatic worldwide disparity between high- and low-income countries in the care of patients with epilepsy, and between rural and urban areas (12). This situation is very similar to that of Honduras, according to epidemiological research to date (4-9).

In the last few years, many countries have undertaken initiatives to reduce the treatment gap for epilepsy (12). In 1994, the Honduran Epilepsy Society was formed as a chapter of ILAE; 1995 saw the formation of the Honduran Neurology Association as a chapter of the World Federation of Neurology; in 2008, Honduras was chosen as the demonstration center for the Global Campaign Against Epilepsy; and a protocol for the comprehensive management of epilepsy at the primary care level was published in 2010 (14).

In 2014, the third study in the rural community of Salamá, in the department of Olancho, was concluded; the study examined the epilepsy treatment gap in that community. This was a longitudinal epidemiological study of community (cohort) intervention, and was designed to determine the impact of the intervention on the treatment gap and on the prevalence of the disease. It was carried out in three stages, as follows:

- In the first stage, a medical team performed a house-to-house screening of the entire municipality of Salamá, covering 1,489 dwellings and a population of 5,545, to identify suspected cases of epileptic seizure.
- The second stage employed a second instrument to screen for and diagnose epileptic seizure in suspected cases.
- The third stage involved a neurological evaluation and electroencephalogram to validate the diagnosis of epilepsy and to determine the treatment gap.

The prevalence of epilepsy was found to be 20/1,000, with active epilepsy at 15.8/1,000 and inactive epilepsy at 4.2/1,000. Disaggregation by gender showed the rate among women to be 17.1/1,000 and the rate among men to be 23.2/1,000. The treatment gap for active epilepsy was 53%. After 17 years of community intervention in Salamá, with education, the creation of a maternal and child clinic, and awareness building efforts, the treatment gap fell from 53% to 13% (7).

### III. Conclusions

1. Preventable conditions such as NCC and perinatal trauma are the major causes of epilepsy in Honduras.
2. Coordinated work by representatives from academia (the graduate program in neurology at the UNAH School of Medical Sciences), the Secretariat of Health, and the community itself, with support from PAHO, among others, has produced positive results that are sustainable in the long term, and that constitute an improvement in the management of epilepsy in Honduras.
3. Epidemiological studies on epilepsy during nearly two decades in Honduras have provided increased knowledge on the disorder, and have led to community interventions that reduced NCC and narrowed the treatment gap for the disease.

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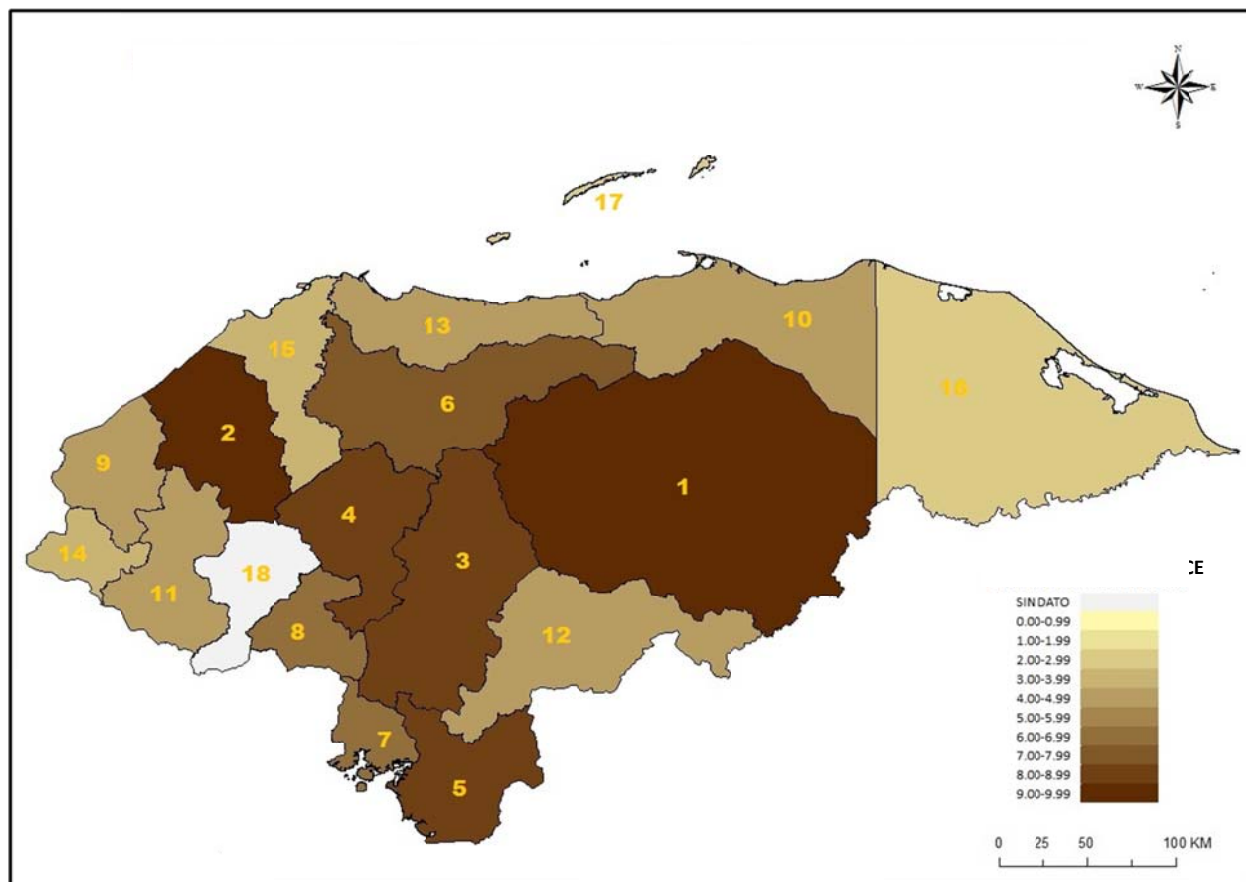


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## ANNEX

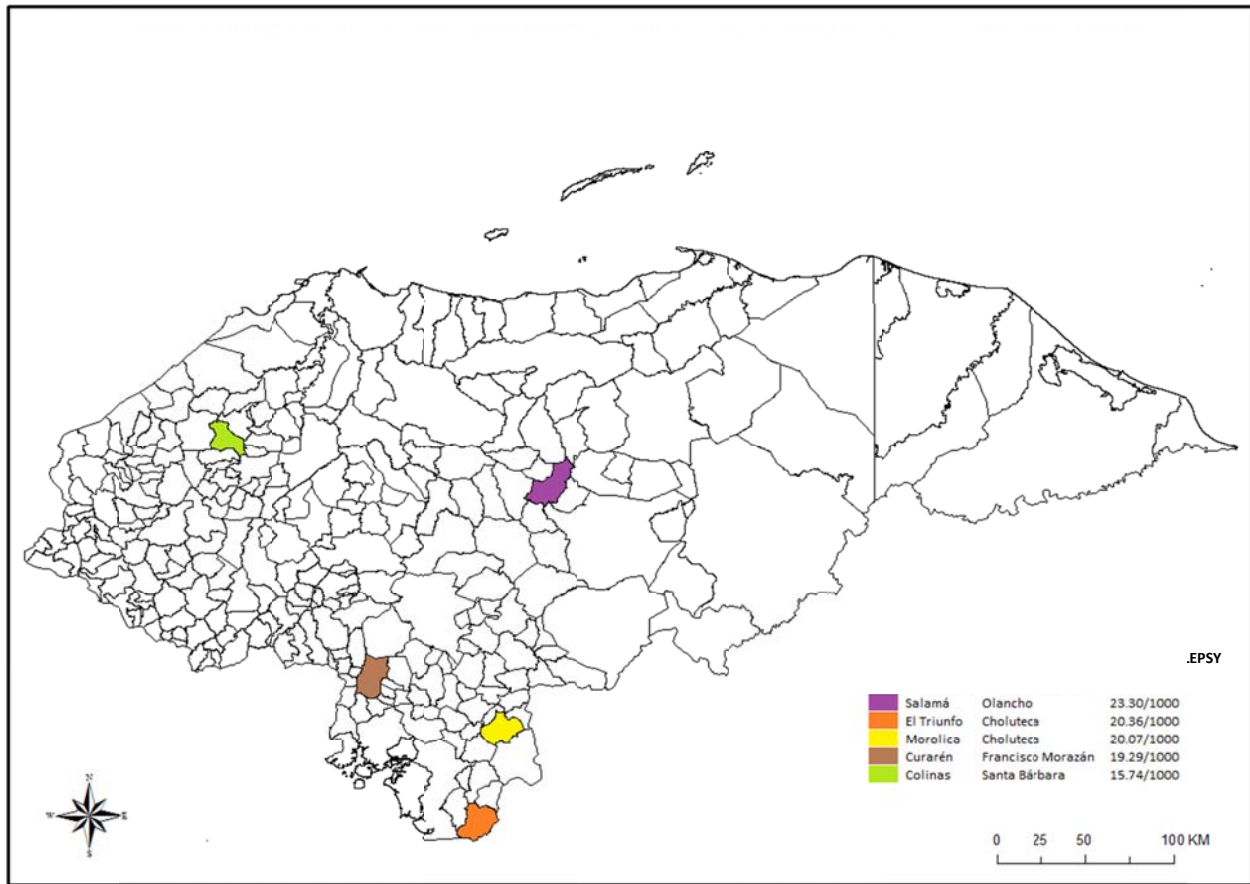
### FIGURES AND TABLES

Figure 1. Prevalence of epilepsy in Honduras per 1,000 inhabitants and by department, in descending order.



Map of Honduras and its departments: 1. Olancho (9.23); 2. Santa Bárbara (9.17); 3. Francisco Morazán (8.52); 4. Comayagua (8.20); 5. Choluteca (8.09); 6. Yoro (7.25); 7. Valle (6.39); 8. La Paz (6.29); 9. Copán (4.7); 10. Colón (4.47); 11. Lempira (4.36); 12. El Paraíso (4.10); 13. Atlántida (4.06); 14. Ocotepeque (3.92); 15. Cortés (3.40); 16. Gracias a Dios (2.7); 17. Islas de la Bahía (2.24); 18. Intibucá (no data).

**Figure 2. Municipalities in Honduras with the highest prevalence of epilepsy**



**Table 1. Etiology of active epilepsy in patients studied, by age group**

Etiology/age groups	0-9	10-19	20-29	30-39	40-49	50-59	60+	Total	%
Cryptogenic	7	8	3	3	2	3	1	27	30.0
Idiopathic	3	4						7	7.8
Symptomatic	7	21	8	6	9	3	2	56	62.2
Neurocysticercosis	4	13	5	3	6	1	1	33	36.6
Perinatal brain injury		5	1	1				7	7.8
Post-ECV					1		1	2	2.2
Cortical dysplasia	1			1				2	2.2
Post-traumatic	2	1						3	3.3
Post-meningitis/ Encephalitis			1		1			2	2.2
Multiple factors		1			1			2	2.2
Other <sup>a</sup>		1		1	1	2		5	5.6
<b>Total etiologies</b>	<b>24</b>	<b>55</b>	<b>18</b>	<b>15</b>	<b>21</b>	<b>9</b>	<b>5</b>	<b>90</b>	<b>100.0</b>

<sup>a</sup>The "Others" category includes one tumor (probable meningioma), non-cysticercosis granuloma, sequelae of chronic alcoholism, chronic hydrocephalia, and progressive myoclonic epilepsy (probable Unverricht-Lundborg disease).

Source: Medina MT et al. (5)

**Table 2. Incidence per 100,000 inhabitants of new cases of active epilepsy and neurocysticercosis after eight years of monitored implementation of community intervention measures in the community of Salamá beginning in 1997**

Year	Total population	Cases of epilepsy <sup>a</sup>	Incidence of epilepsy (per 100,000)	Epilepsy due to cases of NCC <sup>b</sup>	Incidence of epilepsy due to NCC (per 100,000)
1998	6365	5	78.6	0	0.0
1999	6257	2	32.0	1	16.0
2000	6149	5	81.3	1	16.3
2001	6041	5	82.8	2	33.1
2002	5933	7	118.0	0	0.0
2003	5825	6	103.0	1	17.2
2004	5717	4	70.0	0	0.0
2005	5609	2	35.7	0	0.0

<sup>a</sup> There were 36 new cases in the 8-year period of monitoring, with an average of 4.5 new cases annually, and average annual incidence of 75.2/100,000 for the period.

<sup>b</sup> Taking into account symptomatic epilepsy secondary to the reduction of neurocysticercosis (NCC) in the last four years of the period studied, along with a reduction of incidence during that period.

Source: Medina MT et al. (6)

**Table 3. Etiology of the 36 new cases of active epilepsy that appeared during the study that began in the Salamá community in 1997.**

Etiology of epilepsy	1998	1999	2000	2001	2002	2003	2004	2005	Total n (%)	n (%) in 1997	Value of p
Cryptogenic	3		3	3	1	1	2		13 (36.1)	27 (30.0)	NS
Idiopathic	1					1			2 (5.6)	7 (7.8)	NS
Symptomatic	1	2	2	2	6	4	2	2	21 (58.3)	56 (62.2)	NS
Neurocysticercosis		1	1	2		1			5 (13.9)	33 (36.7)	0.02
Perinatal brain injury		1	1		1		1		4 (11.1)	7 (7.8)	NS
Post-ECV					1				1 (2.8)	2 (2.2)	NS
Cortical dysplasia	1							1	2 (5.6)	2 (2.2)	NS
Post-cranial trauma						1	1		2 (5.6)	3 (3.3)	NS
Post-meningitis/Encephalitis								1	1 (2.8)	2 (2.2)	NS
Multiple factors <sup>a</sup>					2	1			3 (8.3)	2 (2.2)	NS
Other <sup>b,c</sup>					2	1			3 <sup>b</sup> (8.4)	5 <sup>c</sup> (5.6)	NS
Total	5	2	5	5	7	6	4	2	36	90 (100)	

<sup>a</sup> Etiology is considered to be multiple-factor when the simultaneous presence of more than one verified condition correlates with the type of seizure and hour at which the epileptic seizure began and there are no criteria to exclude any of the conditions as a cause.

<sup>b</sup> Temporal mesial sclerosis (2); nonspecific white-matter injury (1).

<sup>c</sup> Tumor (1); alcoholism (1); progressive myoclonic epilepsy (1); chronic hydrocephalus (1); non-neurocysticercosis granuloma (1).

Source: Medina MT et al. (6)

## VII EPILEPSY PRIORITY PROGRAM IN MEXICO

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Dr. Mario Alonso Vanegas, Neurosurgeon, Chair of the Latin American Epilepsy Surgery  
Subcommittee (Mexico)

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### I. Introduction

Mexico's Epilepsy Priority Program (known by the Spanish acronym PPE) was created in October 1984 to regulate, coordinate, systematize, and optimize strategy and actions to gain a better understanding of, and to more effectively respond to, the problems of persons with epilepsy and their families.

The PPE is composed of representatives from various sectors (Secretariat of Health; Mexican Social Security Institute, or IMSS; Institute for Social Security and Services for State Workers, or ISSSTE; National Institutes of Health, or INS; Government of the Federal District; Petróleos Mexicanos, or PEMES; and several of the country's university hospitals), and has already succeeded in creating 65 Comprehensive Epilepsy Care Centers (known as CAIEs) throughout the country incorporated within hospitals. The PPE draws on advice and support for research, as well as teaching, from the National Autonomous University of Mexico (UNAM) and the National Polytechnic Institute (IPN).

One essential strategy of the PPE is to optimize the care of epilepsy sufferers and their families by training primary care medical personnel to improve diagnosis and treatment when the patient first makes contact with the pediatrician or general practitioner. Support from the Comprehensive Epilepsy Care Centers (CAIEs) is available for this purpose.

Approximately 7% to 8% of the Mexican population is estimated to suffer from some type of neurological disorder. Available data suggest that neurological disorders account for 10% of hospitalizations annually. Of the neurology patients who consult the National Institute of Neurology and Neurosurgery (INNN), 28% do so for epilepsy (1).

Studies at the INNN have shown the magnitude of the epilepsy problem, indicating a prevalence of 1% to 2% in the population. There was a 1.8% prevalence of epilepsy among 9-year-old school children in the administrative borough (or "delegación") of Tlalpan, in the Federal District. Comparable prevalence was found in suburban populations (Santa Úrsula, Federal District) and in rural populations (San Miguel Tecamatlán, State of Mexico; Comalcalco, Tabasco; Naonilco, and Copala) (2, 3, 4) (Figure 1). These studies were conducted by the

Neuroepidemiology Department of INNN, following the criteria established by the Commission on Classification and Terminology of ILAE (5).

**Figure 1. Epilepsy in Mexican Schoolchildren**

Year	Finding	Reference
1983	Schoolchildren in Tlalpan, Federal District Prevalence: 18.3/1,000	Neuroepidemiology 2:16-23,1983
1991	23,000 schoolchildren, Mexico Prevalence: 10.8/1,000	Epilepsia vol.3.2 suppt.1 1991 p. 111
1992	Naolinco, Veracruz Prevalence: 11/1,000	INNN records, 1993, vol. 8, no. 3
1993–1994	Comalcalco, Tabasco Prevalence: 20/1,000	Personal communication
2002	Copala, Guerrero Prevalence: 15.6/1,000	Personal communication

Source: Neuroepidemiology Department, National Neurology and Neurosurgery Institute (Mexico).

**In summary, experience in Mexico indicates that:**

- The prevalence of epilepsy is 1% to 2%.
- The social labeling and stigmatization surrounding the disease makes it difficult to detect, since it is frequently hidden.
- 50% of epilepsy sufferers only consult a specialist several years after the onset of seizures.
- The resources devoted to medical, social, and rehabilitation services for persons with epilepsy, as well as to research, are limited and dispersed.
- The cost of care for persons with epilepsy is high. Various factors are responsible for this, including: the extended course of the disease; the often costly or inaccessible long-term medication; and the lack of patients’ productivity, due not to personal failures, but rather to rejection by the society (40% of cases).
- School dropout is one example of the social impact of epilepsy. Of children aged 9 diagnosed with epilepsy, only 48% were still in school seven years later (versus 79% of the non-epileptic control group). A similar pattern occurs in relation to unemployment/underemployment among epileptics.
- Between 15% and 20% of persons with epilepsy are partially or totally dependent.

**II. Objectives and structure of the PPE**

**General objective:** To improve the quality of life of persons with epilepsy.

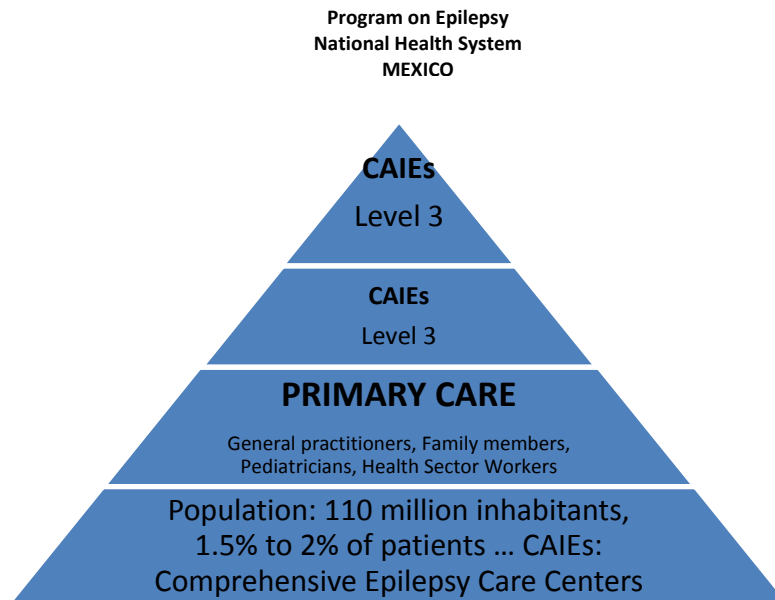
### Specific objectives:

- To reduce the incidence and prevalence of epilepsy through preventive measures and care.
- To establish an educational program to eliminate prejudices and stigma surrounding epilepsy.
- To promote programs of epidemiological research that are longitudinal, analytical, and prospective for high-risk groups, so that the findings help in addressing the national problem.
- To develop viable mechanisms to import, manufacture, and distribute effective and inexpensive antiepileptic drugs, and to provide support for the development of new drugs.
- To increase the number of CAIEs throughout the national territory.
- To design and implement continuing educational programs to train human resources in the health field and at the community level.
- To strengthen the legal basis for protecting the rights of persons with epilepsy.

### Structure

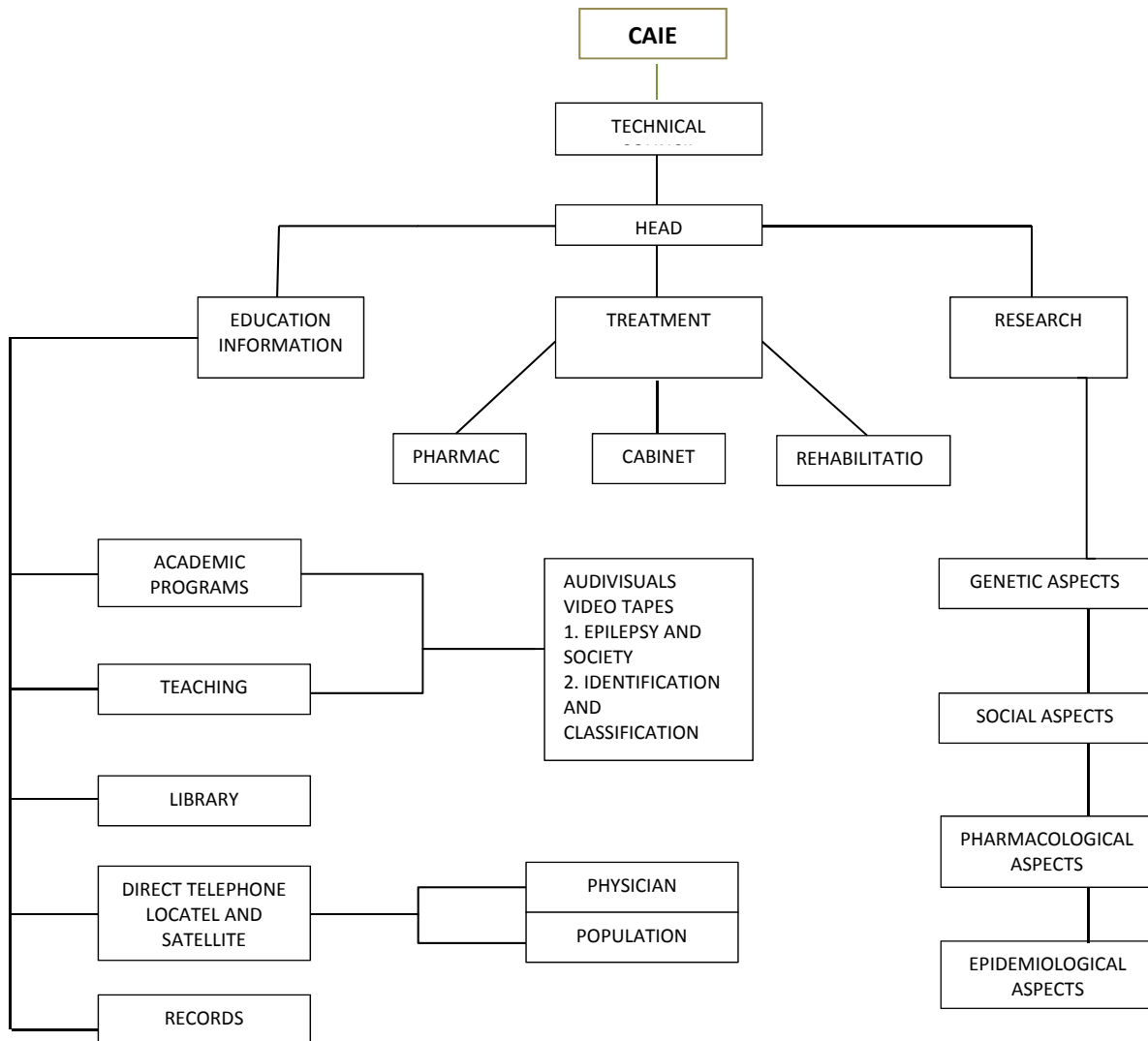
The PPE has a Technical Council composed of representatives of the above-mentioned institutions: SSA, INNN, ISSSTE, IMSS, Government of the Federal District, PEMEX, Instituto Politécnico Nacional (IPN), INS, and UNAM. Figures 2 and 3 show the PPE pyramid and the organizational chart of the Comprehensive Epilepsy Care Centers (CAIEs).

**Figure 2. Priority Program on Epilepsy (PPE)**



CAIEs: Comprehensive Epilepsy Care Centers

**Figure 3. Comprehensive Epilepsy Care Centers (CAIE)**



### III. Strategies and other components of the PPE

#### Strategic lines

- Intersectoral and interinstitutional approach.
- National coverage.
- Delimitation of priority responsibilities.
- Identification of high-risk groups and prioritization of actions.
- Creation of Epilepsy Modules – places that provide information and where persons with epilepsy can be referred on to care centers or services.



- Seven regional epilepsy meetings yearly, and one annual course to be held by each of the CAIEs, in order to optimize referral and counter-referral of persons with epilepsy.
- Regionalization of CAIEs.

### **Education programs**

The objective of the education programs is to build awareness and inform the population, so that people have a better understanding of persons with epilepsy and their families. The programs include dissemination and discussion in the mass media.

The education programs are designed for the general population or for specific groups such as: persons with epilepsy and their families, pregnant women, students, teachers, and civil servants. Health professionals and technicians need programs for training on epilepsy as part of a continuing education strategy.

### **Thematic areas of research**

- Impact of epilepsy on the epileptic and his/her family
- Epidemiology
- Case studies of high-risk cases
- Pharmacological experimentation
- Common ideas about epilepsy
- Causes of epilepsy
- Diagnosis, treatment, and control of epilepsy
- Prevention of epilepsy
- Epilepsy among inmates
- Epilepsy among pregnant women and newborns
- Factors that predispose people to, and trigger, seizures
- Electrographic methods
- Participatory therapy
- Effects of education and behavioral change programs
- Congenital malformations and epilepsy
- Epilepsy and sexuality
- Alcohol and epilepsy
- Epilepsy and alterations in language
- Genetics

### **Evaluation and control**

The PPE requires that methods and techniques be designed to supervise, evaluate, and control the objective and timely assessment of efforts toward the proposed objectives, goals, and actions.

#### IV. Final considerations

It is estimated that 15% of the population experiences at least one convulsive seizure during their lifetime. However, convulsive seizures may have different causes, such as metabolic disorders and hyperthermia (febrile seizures). Pseudo-seizures related to other neurological or mental dysfunctions can also occur. Epilepsy is thought to represent 50% of the cases of convulsive disorders.

Epidemiological studies, particularly those measuring prevalence, are useful in determining care needs for epileptics, and in planning health programs, as well as for implementing educational and other interventions.

WHO emphasizes the need to view epilepsy as a public health problem, due to its scope and importance. In Mexico, there is a pressing need to organize a health program to address and respond to the needs of persons with this disorder.

All data on Mexico's Epilepsy Priority Program can be accessed at:  
[www.epilepsymexico.gob.mx](http://www.epilepsymexico.gob.mx).

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## VIII

# THE EXPERIENCE OF BRAZIL: THE DILEMMA OF HERMES AND THE DEMYTHOLOGIZING JAGUAR

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### I. Introduction

Two famous “Hermes” inhabit the mythological and philosophical imagination of the West: the Greek and the Egyptian versions. Both symbolize communication and divine messages.

The first Hermes is a god in the ancient Greek mythological tradition. One of Zeus’s sons, he is represented as Mercury in Roman mythology. In addition to being the god of communication, he is considered the patron god of, among other things, trade, the arts, and science.

The Egyptian Hermes is the product of the religious syncretism of the Hellenistic period in Egypt, when Greek and Egyptian mythologies mingled. Considered by some to be a god, by others a wise man, the Egyptian Hermes is known as Hermes Trismegistus, or “thrice blessed Hermes,” and is a combination of the Greek god Hermes and Egypt’s Thoth, the god of wisdom.

Although both of these Hermes are messengers and protectors of communication, they are different in one important way: in the Egyptian legend, Hermes Trismegistus is the creator of a magic seal that prevents air from entering containers that carry things divine. This is the apparent origin of the word “hermetic.”

How, then, is communication broadly construed to be reconciled with hermetic, selective communication? This dilemma of “gods” has a parallel in human life. In earthly existence, what is the “must be”? Is it knowledge for all, or knowledge circumscribed for certain groups? In the case of health information, in particular, the paths taken in this regard can have very positive or negative impacts on individuals.

This chapter discusses the communication of scientific subjects related specifically to epilepsy. It emphasizes interaction between experts and the lay public as a way of democratizing access to information. The text reflects the experience of creating the E-Jaguar website (a PAHO/WHO-ILAE-IBE undertaking), which is an online platform providing easy access to information on

epilepsy for the general public, allowing for the dissemination of knowledge to people with this disorder, their families and caregivers, and non-specialist physicians.

## **II. The riddle of the Sphinx**

Throughout history, access to information has gravitated from “open” to “closed” and back again. Modern recovery of ancient knowledge opened the door to what is now popularly known as the “information age,” in which knowledge that was earlier limited to the private or secret sphere became increasingly part of the public domain.

At no previous time in history has the world been so small (Hobsbawm, 2006). Although distances remain the same geographically, in terms of communication, they have shrunk irreversibly. The unprecedented scientific and technological developments of the 20<sup>th</sup> century have made instant communication between any points on the globe possible.

You, the reader, are probably a user of social networks, email, etc.; speaking with someone on the other side of the world is simple, cheap, and instantaneous. According to the International Telecommunication Union, in 2015 some 3.2 billion people, over one third of the world’s population, are estimated to have access to the internet, and 68.75% of these are in developing countries. In the Americas, the number of users is around 651 million, more than half of the continent’s total population (ITU, 2015). In a world of infinite possibilities for sharing knowledge and experience, however, the potential of the internet is still under-exploited with regard to the dissemination of scientific knowledge.

In a well-known passage from Sophocles’s Oedipus Rex, the main character must face the Sphinx, which gives him a riddle with the condition that if he fails to guess the answer he will be devoured. You, then, the doctor or scientist working on subjects that relate directly or indirectly to human life, and knowing all the potential that today’s communications media offer: What would your answer be if you had to confront the Sphinx and explain why the communication age is not being used as fully as it might be to promote scientific knowledge?

## **III. Science as a public network**

Certain elements are essential for understanding the communication process: (i) the sender, who creates and articulates (ii) a message to (iii) a recipient, making use of (iv) a code, through (v) a communication channel.

In scientific communication today, a great number of communication channels are available, ranging from traditional media such as printed newspapers, magazines, books, television, and radio, to the more recent media that have arisen with the evolution of the communications media, such as SMS, email, websites, blogs, social networks, etc. Social networks in particular are very efficient platforms for disseminating information, due to the large number of users. At the end of May 2015, Facebook had 1.44 billion active users (Facebook, 2015), while Twitter

currently has 302 million active users, with over 500 million “tweets” being sent daily (Twitter, Inc., 2015).

A message consists of the set of informational items that are transmitted and can be expressed in various ways, not only in scientific articles and press releases, but also in the form of comics, educational books, television programs, texts for younger audiences, etc. The forms of transmission and communication channels for a message are chosen based on the recipient.

The recipient is the target audience. Magazines, websites, blogs, and specialized jargon are the best means of addressing technicians or scientists. The number of scientific publications grows each year. Between 2005 and 2009, approximately 3.8 million technical and scientific documents were published<sup>4</sup> worldwide, of which 1.3 million were from the Americas (World Bank, 2015).

However, for addressing lay audiences, publications of this type are less than ideal; instead, channels that habitually use simple, explanatory language are the preferred medium. The importance of language in transmitting information to the general public cannot be underestimated. Making the message less complex, giving examples, and using comparisons are ways of reaching greater numbers of people.

Science must be democratized and brought to the largest possible number of people, so that scientific advances can make a (positive) difference. Science is a public good, and as such should be disseminated broadly and without restriction. But to whom?

Senders of scientific information can be members of various professions. Doctors, psychologists, neuroscientists, and other health professionals and technicians, as well as journalists, publicists, and general communicators have the potential to disseminate scientific information. Each of these groups has its pros and cons as disseminators of scientific information. Scientists possess the necessary technical knowledge but are not experts in the art of communication, whereas communicators are masters of how to transmit content but lack expertise in the content they are transmitting.

One possible way to solve this problem is to create a hybrid: scientist + journalist = “scientouralist” (Tambourgi, Toledo, & Min, 2013). Creating this hybrid does not require a laboratory; a simple merging of forces from the two categories is sufficient, whether through collaboration or by a person from one category specializing in the other’s area of expertise.

One example of this can be seen in the specialized courses and Masters in Communication of Science and Neuroscience offered at the State University of Campinas (UNICAMP), in Brazil. There, the classrooms bring scientists and communicators together, giving them the

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<sup>4</sup> This includes articles in the fields of physics, the biological sciences, chemistry, mathematics, clinical medicine, biomedical research, engineering and technology, and Earth and space sciences.

opportunity to complement each other's training and to develop the abilities needed to write clear, easily understood, and accurate scientific content.

Regardless of who the transmitter is – communicator, scientist, or a hybrid – what is important is to bring science to the largest possible audience in a simple and accurate way by using available resources.

#### **IV. Epilepsy**

In 70% of epilepsy patients, the disease can be kept under control by monotherapy with efficient, low-cost drugs. However, most epilepsy sufferers receive no treatment at all. In the developing countries, the treatment gap can cover as high as 75% of cases.

There are various reasons for this problem, but the most obvious include limitations on access to health services and drugs. Precarious access to information is also an important impediment to assessing the clinical condition of patients.

We speak of two types of information: preventive and remedial. Information on prevention is important in epilepsy, since in most cases the disease is acquired. The best form of prevention is to avoid situations that can cause the disease, but this is not always possible. Thus, remedial information is necessary too, in order to help people struggling with epileptic symptoms.

In this context, information falls into two further categories: clinical and social. It is important to provide answers to questions such as (but not limited to): What are the symptoms? What type of doctor should I seek? What treatments are available? How long does treatment last? What should be done in the case of a seizure? Despite the importance of these questions, the social aspect is probably the most important to communicate, and should be addressed in order to help the patient integrate in society.

#### **“I don't believe in witches, but they do exist. Or do they?”**

Epilepsy is one of the earliest neurological diseases to be recognized by the scientific community, and it affects around 1% of the world's population. Because of the characteristics of epileptic seizures, sufferers are subject to widespread social discrimination.

Seizures are alarming to observers. What, then, should an observer do? Many questions arise in the minds of people who witness a seizure: What causes a seizure? What does the person have? Is it contagious? These concerns influence their attitude to the sufferer. Sometimes failure to take action is not the most serious problem.

Seizures tend to be associated in the popular mind with demonic or paranormal activity. Curiously, epilepsy in the past was associated with predestination and power, as in the case of Julius Caesar. Today, it is associated with the “dark side of power.”

Modern inquisition: the *auto-da-fé* is out; discrimination is in. One of the worst problems confronting people with epilepsy is “social death,”<sup>5</sup> i.e., exclusion by the community, and even by the family. Stigma and prejudice are present on a constant daily basis.

One effect of this is that many epilepsy sufferers drop out of school or leave the workplace. In an ideal scenario, schoolmates/workmates and teachers/bosses would collaborate more fraternally with the student/worker in confronting epilepsy, by providing help and emotional support, particularly during and after a seizure. In an environment where there is a lack of information, experiencing a seizure in the middle of a class can be highly embarrassing: some people laugh; others are afraid; most leave.

The situation can also be difficult within the family. Parents or family members, rather than accepting the reality of the disease, segregate the patient, creating psychological difficulties that can be lifelong if not adequately treated.

In short, information not only contributes to preventing the disease; it also helps the person struggling to live with epilepsy, while creating a social environment in which there is greater knowledge and respect.

#### **V. The PAHO-ILAE-IBE partnership**

This is an unprecedented, promising, and historic initiative. On 14 November 2012, Quito, Ecuador was the site for the signing of the Memorandum of Understanding that created the tripartite PAHO-ILAE-IBE coalition, partnering a specialized organization of the United Nations System (PAHO/WHO) with international civil society organizations representing the medical/scientific field (ILAE) and persons with epilepsy (IBE).

The objective of this shared effort is to give priority importance to addressing epilepsy, and to ensure that the disease is recognized as a public health problem in the countries of the Americas. It also serves as an example for new campaigns and programs in other parts of the world.

In 2011, the Directing Council of PAHO approved the Strategy and Plan of Action on Epilepsy.<sup>6</sup> This document was produced jointly by PAHO, ILAE, and IBE. The Region of the Americas is the first world region in which, through consensus among all of the governments, a plan of action to improve the living conditions of persons with epilepsy was adopted. The PAHO Strategy and Plan of Action on Epilepsy is slated to last ten years, and establishes a set of concrete goals to be achieved by 2021.

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<sup>5</sup> This term was coined by the Brazilian jurist Edmilson Fonseca, a vehement defender of the human rights of people with epilepsy.

<sup>6</sup> The text is available in Spanish, English, and Portuguese. All versions can be found on the PAHO website at: <http://www.paho.org/>.

Making epilepsy a priority on the health agendas of the Americas means, among other things, improving access to health services, developing specific legislation, promoting education, and increasing research.

## **VI. The demythologizing jaguar**

The jaguar is a feline native to the Americas. It is the third largest in the world, surpassed only by the tiger and the lion. It is ferocious and voracious, and is an efficient hunter. The word “jaguar” was chosen as a name for the website created by the PAHO/WHO-ILAE-IBE partnership, which is designed as a source of relevant, accurate, and reliable information on epilepsy.

It is targeted to persons with epilepsy and their families, non-specialist physicians, caregivers, and other interested parties. The word “jaguar” is written identically in all of the languages of the American continent and the animal has mythic importance among the indigenous peoples because of its ability to move in the shadows.

One of the website’s objectives is to present both preventive and remedial information. E-Jaguar is a virtual platform that promotes communication networks and interaction between people and organizations in the Americas that deal with epilepsy. It is one of the main promotion and prevention tools created in connection with implementing the Strategy and Plan of Action.

Its chief objectives are: (1) to increase the public’s access to information on prevention; and (2) to help build awareness within the population about what epilepsy is, so as to reduce prejudice and stigma.

Although still in development, the website is accessible to the public at [www.e-jaguar.org](http://www.e-jaguar.org). The site identifies itself, visually, with a symbol that was specially developed by an indigenous Brazilian tribe, the Wayanas, at the request of the E-Jaguar communications team. The logo represents the “Two-headed Jaguar” and serves as a visual accompaniment to the slogan “Stand Up for Epilepsy,” which was created by ILAE and IBE (Min, Tambourgi, & Delmondes, 2013).

### **Content**

The website’s content includes both remedial and preventive information. Content already available includes: What is epilepsy? How can you help a person having an epileptic seizure? What should you not do during a seizure? Symptoms? Diagnosis? Exercises? Additional content covers: supplementary examinations; epilepsy statistics; prevention; myths and truths; elders; treatment; surgery; epilepsy in women; and teachers and educators.



The content is produced and reviewed jointly by journalists and scientists. The site aspires to become a trusted, reliable source of accurate information.

All of the information will be available in the four principal languages spoken in the Americas (Spanish, French, English, and Portuguese); thus, language will not be a barrier to accessing the information.

## **Networks**

E-Jaguar uses social networks, taking advantage of three aspects of this medium:

1. They are dynamic. Due to the ease of transmission, the most up-to-date content can be published on the social networks, whereas updating the website takes more time. At present, E-Jaguar is only on Facebook.
2. They are interactive. The use of social networks allows for more interaction with the public and within the networks. It makes possible real-time sharing of experiences, contacts, and opinions.
3. They provide variety. Social networks provide another approach and mechanism for disseminating and publicizing the website's information.

## **Mapping changes and developments**

The site has a map of the Region that includes individual country data on national associations, legislation, services, and specialized physicians to contact for treatment.

Representatives will be chosen from each country to provide and update information. They will receive questionnaires to complete periodically, which will provide information on progress in implementing the Strategy and Plan of Action on Epilepsy, making it possible to more closely monitor progress and identify problems in the countries.

## **Next steps**

The website is now operational. The next steps include:

- expanding the content;
- translating content into all four languages (English, Spanish, French, and Portuguese);
- developing the site's capacity for uploading and downloading educational material;
- obtaining data from all countries in the Region; and
- sending out questionnaires to obtain information about progress achieved.

## From the Emerald Tablet to the Amethyst Tablet

Hermes Trismegistus, the carrier of communications, is credited with creating the Emerald Tablet, a short cryptic text written in precious stone that transmits philosophical teachings on the human soul.

Positing a parallel with epilepsy, we propose to create an Amethyst Tablet that establishes scientists' and communicators' commitment to continue and expand scientific communication on epilepsy, ensuring that communication will not stop at words, but will become action. Ultimately, this is the point of the message: to create positive changes in the world for persons with epilepsy.

Amethyst is purple, a symbol of the "Pan American Day Against Epilepsy." May that day's message be repeated daily and into the future!

## VII. Final considerations

This chapter emphasizes the importance of using scientific communication as a tool to educate and alert the lay public about epilepsy and related issues. This text is an invitation to practice scientific disclosure; it offers some suggestions for ways to bring information on epilepsy to a wider public.

Some final and essential points:

1. Informing the greatest possible number of people about epilepsy is crucial. Lack of information is an impediment to prevention, and increases prejudice and stigma.
2. The E-Jaguar website is intended as a weapon to fight misinformation. Much remains to be done, but the commitment to changing the current realities is firmly in place.
3. It is recommended that communicators, scientists, and "scientouralists" view knowledge as an opportunity to create, dare, and serve as a multiplier.
4. The more accurate the information received, the better the lives of persons with epilepsy, and the more dignity they will enjoy.

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## IX

### EXPERIENCES WITH LEGISLATION ON EPILEPSY: COLOMBIA AND ARGENTINA

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#### **Law No. 25.404 on Epilepsy – ARGENTINA**

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Dr. Silvia Kochen and Jorge Lovento submitted this bill, as individuals, to Argentina's Chamber of Deputies in 1999. It was approved on 8 March 2001, and regulations to implement it were put in place in 2009.

Relevant substantive portions of the law's text include the following:

ARTICLE 1 – This law guarantees all persons suffering from epilepsy the full exercise of their rights, prohibits any discriminatory act against such persons, and provides special measures of protection required by the condition of epilepsy.

ARTICLE 2 – Epilepsy shall not be considered an impediment to applying for, undertaking, and performing work, except as provided for in Article 8.

ARTICLE 3 – All epilepsy patients have the right to education at all levels, without any constraint due to their disease.

ARTICLE 4 – Epilepsy patients have a right to comprehensive and timely medical care, with all of the technological advances provided by science and the healing arts.

ARTICLE 5 – Epilepsy shall not be considered in itself to be a disease that increases the risk of accidents, in the context of services provided by life and/or health insurance entities.

ARTICLE 6 – Ignorance of the rights provided by articles 2, 3, and 5 of the present law shall be considered an act of discrimination as defined by Law 23.592.

ARTICLE 7 – The medical and social services to which the present law refers are incorporated with full legal effect in the Mandatory Medical Program approved by Resolution 247/96 of the Ministry of Health and Social Action, without prejudice to the application, where relevant, of the provisions of Laws 22.431 and 24.901 and the regulatory and supplementary provisions thereof.

ARTICLE 8 – When so requested, the treating physician shall provide the patient certification of his/her ability to work, indicating, if necessary, any relevant limitations and recommendations.

ARTICLE 9 – In any judicial or extra-judicial dispute in which the fact of being epileptic is invoked to negate, modify, or extinguish rights of any type, the opinion of the professionals in the program referred to in Article 10 of the present law shall be a sine qua non, and may not be replaced by other evidentiary measures.

ARTICLE 10 – The Executive Branch, through the Ministry of Health and Social Action as the enforcing authority for this law, without prejudice to other objectives established by regulations, shall conduct a special program on epilepsy with the following objectives:

- a) To understand all aspects of research, teaching, prevention, diagnosis, treatment, and monitoring of the disease in its medical, social, and labor dimensions;
- b) To issue regulations which, in the context of the Ministry's authority, permit optimal fulfilment of the purpose of this law;
- c) To conduct statistical studies covering the entire country;
- d) To conduct educational campaigns for the community in general, and for specific groups, in order to create awareness about the disease, alert people to the need for timely treatment, and prevent discrimination against sufferers of the disease;
- e) To offer scientific and technical collaboration to provincial authorities and authorities of the City of Buenos Aires for developing regional programs;
- f) To promote the establishment of international agreements, in particular with the countries that are signatories to the Treaty of Asunción, to formulate and develop common programs relating to the objectives of this law;
- g) To enter into agreements for relevant mutual collaborations with provincial authorities and authorities of the City of Buenos Aires.
- h) To provide insurance for patients with no medical/social assistance coverage who lack economic resources, so that they receive necessary medication at no cost;
- i) To carry out all other actions arising from the provisions of this law and its regulations.

ARTICLE 11 – All regulations contradictory to the provisions of this law shall be null and void.

ARTICLE 12 – The expenditures required by this law shall come from credits for the budget item of the Ministry of Health and Social Action.

ARTICLE 13 – The province and City of Buenos Aires are encouraged to create regulations of a similar nature for their respective jurisdictions.

ARTICLE 14 – To be communicated to the Executive Branch.

## Decree 53/2009 (27/1/2009)

This decree constitutes the uniform regulatory framework for the diagnosis and treatment of persons with epilepsy. Copied below are its substantive elements:

Art. 1 — Discrimination, for the purposes of Article 1 of Law 25.404, shall be construed as being any invocation that expressly or implicitly limits a person with epilepsy from the full exercise of his/her rights to obtain or keep a job, or to access jobs in the public sector. Such person shall also have free access to health education services and any other public social or promotional services.

Art. 4 — The enforcement authority shall assist jurisdictions that lack the necessary capacity to develop programs for the care of patients, where such programs are not in place. Such assistance includes diagnostic practices and the provision of first- and second-line drugs for epileptic patients without health care insurance who lack economic resources. The Ministry of Health shall establish the relevant budget lines for the purpose of providing necessary second-line drugs in cases where they are not covered by a specific program of the jurisdiction's health authority.

The provision of medications and other elements of diagnosis and treatment to serve patients' needs shall be funded with the specific credits earmarked for social security and those of other, private health care systems.

Art. 5 — The provisions of Article 5 of Law 25.404 shall be enforced by the National Institute Against Discrimination, Xenophobia, and Racism.

Art. 7 — The professional responsible for providing the certificate of ability to work shall consider the type of epilepsy from which the applicant suffers, as well as the nature of the tasks to be carried out, or that are being carried out, so that such activity does not jeopardize the physical integrity of the patient or of third parties...

Art. 9 — The program referred to in Article 9 of Law 25.404 shall be conducted under the Ministry of Health's Secretariat of Health Promotion and Programs of the Ministry of Health. It shall include a Technical Committee to provide advice on issues related to the substance of the present law. Its members shall be designated by the Enforcement Authority, and they shall fulfill their function ad honorem, without prejudice to remuneration that they may receive in connection with their respective posts.

The Ministry of Health shall conduct a survey in the various jurisdictions of the national territory to determine which ones have appropriate programs for treating epilepsy, and shall, through the Federal Health Council (COFESA), urge all jurisdictions to develop such programs...

## Technical Committee on Epilepsy

The Committee is composed, among others, of representatives of the Argentine League Against Epilepsy (LACE), the Epilepsy Group of the Argentine Neurological Association, the Child Neurology Society, the Epilepsy Foundation (FUNDEPI), representatives of the regions (Cuyo Region, Northeast Region; Central Region; Northwest Region; Southern Region), and experts in the field.

On 17 April 2009, pursuant to the resolution to create the Technical Committee on Epilepsy, it was established that:

- The Committee will take the relevant measures to disseminate knowledge of the Epilepsy Law and will call on the various provinces to comply with it.
- The Committee will establish the linkages needed for joint actions to eliminate discrimination against persons with epilepsy and to facilitate access to timely and appropriate diagnosis and treatment.
- The Committee will resolve to adhere to the Clinical Practice Guidelines of the International League Against Epilepsy and the Guidelines of the Epilepsy Group of the Argentine Neurological Association.
- The Committee will assign each of the subcommittees the task of reviewing said guidelines, for the purpose of establishing National Clinical Practice Guidelines for Epilepsy.

## Final considerations on the current status of implementation of the law and associated regulatory decree

- The national Ministry of Health has not fulfilled the provisions established in 2009.
- The professionals dedicated to caring for epileptics have worked individually, and/or as representatives of the centers or institutions where they work, on implementation of the national law.

## Additional information:

The complete text of the law can be found on the following websites:

[www.cefundepi.org.ar](http://www.cefundepi.org.ar)

[www.alae.org.ar](http://www.alae.org.ar)

[www.biblioteca.jus.gov.ar/legislacion-argentina.html](http://www.biblioteca.jus.gov.ar/legislacion-argentina.html)

## LAW 1414 - COLOMBIA

Prof. Jaime Fandiño-Franky

Neurosurgeon, driving force behind Law No. 1414/10 (Colombia)

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Colombia's Law 1414 is legislation "through which special measures are established to protect persons suffering from epilepsy, with principles and guidelines established for their comprehensive care." The law works to combat discrimination and stigmatization. It comprehensively addresses education, health, and rehabilitation for persons with epilepsy.

Law 1414 is already a reality in Colombia and can be used as a legal instrument, including in the courts. Passing the law required conviction and numerous efforts, over the course of three years of struggle. A senator, a citizen, and the Constitutional Court together were sufficient to move the process forward.

It is important, however, not to understate the importance of the huge national and international support the process received. Without that support, it would have been extremely difficult to secure passage of the law. Among other sources of support the following are noteworthy:

- Around 50 chapters of ILAE and IBE, including all of the Latin American chapters.
- Susanne Lund, President of IBE, a strong supporter throughout.
- Peter Wolf, Past President of IBE, who wrote letters to the Colombian Legislature.
- Hanneke de Boer, President of the Global Campaign against Epilepsy, who addressed the Colombian Congress and spoke on national television.
- Carlos Acevedo, editor of "Epilepsy News" and Vice-president for Latin America of IBE, who addressed the Colombian Congress and spoke on national television.
- Piet Voskuil, of the Dutch League against Epilepsy.
- Lilia Núñez, Chair of the Latin American Committee of IBE.
- Marco Tulio Medina, Vice-president of ILAE.
- Colombia's scientific associations and the country's National Academy of Medicine.
- 60,000 signatures of persons with epilepsy, gathered over three months.

Finally:

- The Office of the National Prosecutor General and the Constitutional Court, which approved the law.
- The Plenary Congress, which approved the law.
- The President of Colombia, who endorsed the law on 11 November 2010.



How were politicians and the government convinced of the need for this law?

- A leading senator, and that senator's party, committed to the law, after being convinced of the importance of the cause.
- That senator, with support from the party, participated in drafting the law.
- Personal defense and advocacy of the initiative was carried out, including meetings with every member of the legislature (meetings were held with 230 legislators).

Convincing the government was a complex and difficult task: the initiative was opposed from the outset by the Ministers of Social Protection and Finance, and even by the President of the Republic. Even now, there appears to be a degree of indifference about enforcing the regulations. The law provides for the right to petition, and we are working with users and family members to exercise it.

The epilepsy guidelines have already been developed, and we are continuing to work for effective implementation of the law.

#### **Basic features of Law 1414/10 (Colombia):**

1. Discrimination and stigmatization are condemned.
2. Comprehensive health care and rehabilitation are guaranteed.
3. Complete diagnosis and appropriate treatment are guaranteed.
4. Education is promoted.
5. Causes to be addressed, in order to prevent epilepsy, are included.
6. Workplace protection is provided for persons with epilepsy.
7. Lifelong support is provided for epileptics.
8. Rights and obligations are established for persons with epilepsy.

Some substantive aspects of the law are as follows:

#### **CHAPTER I**

#### **Purpose, Principles, Prohibitions, Infrastructure, and Regulation**

**Article 1. Purpose:** The purpose of the present law is to guarantee the comprehensive protection and care of persons suffering from epilepsy.

**Article 2. Definitions:** In applying the present law, the following selected definitions, among others, shall be observed:

**Comprehensive care:** Set of services to promote, prevent, and provide care (diagnosis, treatment, surgical interventions for epilepsy, rehabilitation, and readaptation), as well as provision of the required drugs...

**The comprehensive care process:** ... As a fundamental part of comprehensive management, the caregiver or family group will be given access to training, education, advice, and support, so that they may function as first responders for the patient.

**Prevention:** Integration of measures for early detection of epilepsy, and for monitoring to prevent injury... to reduce the appearance of complications and sequelae...

Also included are technical, scientific, and psychological assistance and support for the caregiver and family group, as first responders, for the initial care of the epilepsy patient, so as to effectively and professionally contribute to the patient's quality of life.

**Article 3. Prohibition:** All natural and juridical persons are prohibited from carrying out or encouraging any discriminatory act in any form directed against a person with epilepsy on account of the disease.

**Article 4. Principles:** The following shall be governing principles for the comprehensive protection of persons with epilepsy:

**Universality...Solidarity...Dignity...Equality**

## CHAPTER II

**Criteria for a public policy of comprehensive care (only selected articles are quoted here):**

**Article 6. Comprehensive programs for the protection of persons suffering from epilepsy:** The Ministry of Social Protection shall require all of the country's health entities and institutions to implement comprehensive programs for the protection of persons with epilepsy, in which there shall be a special section for research, detection, treatment, rehabilitation, registry, and follow-up to comprehensive medical care for all persons with epilepsy...

**Article 9. Funding:** Persons not affiliated with one of the insurance regimes at the time of diagnosis will be provided with care funded by the nation, immediately and effectively, through the Ministry of Social Protection... (comprehensive short-term coverage.)

## CHAPTER III

**Rights and duties of persons with epilepsy (selected articles):**

**Article 16.** Persons with epilepsy shall be protected from all forms of discriminatory, abusive, or denigrating exploitation and regulation.

**Article 20.** Persons with epilepsy who refuse treatment ordered by a physician may not carry out jobs or work that create a risk to society.

**Additional information:**

The complete text of the law can be found on the following websites:

[www.epilepsycolumbia.org](http://www.epilepsycolumbia.org)

<http://www.alcaldiabogota.gov.co/sisjur/normas/Norma1.jsp?i=40746>

## EDUCATION ON EPILEPSY: EXPERIENCES AND REFLECTIONS

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### I. Introduction

Initial considerations:

- Comprehensive and appropriate management of persons with epilepsy requires complementary work by various actors, and setting priorities is essential.
- Training these actors for work at the different levels of the health care system requires the inclusion of specific content in academic curricula.
- Primary care is a basic framework for handling the vast majority of epilepsy sufferers; training health workers at this level is crucial.
- Given that around 30% of cases are drug-resistant, specialized epilepsy facilities should also be developed.
- Establishing and/or strengthening graduate programs in neurology and pediatric neurology is a priority, especially in countries where such programs do not yet exist.
- Establishing specific knowledge objectives for each professional group, adapted to individual country realities, and developing continuing education consistent with those realities, is a challenge to be addressed.
- Educating the population is an essential component of national epilepsy programs. The Global Campaign Against Epilepsy (GCAE) provides a frame of reference for work in this area.

The purpose of this chapter is to provide a brief review of the experience that Uruguay and ILAE have had in developing educational programs (for health professionals, in particular), and to propose some ideas for a regional program in the framework of the PAHO-ILAE-IBE partnership.

Envisioning the problem:

1. What experiences have the Region's countries and institutions had with programs for epilepsy education? What audiences have been targeted, and how have results been measured?
2. How shall a regional education program be planned, in order to incorporate the objectives of the PAHO Strategy and Plan of Action on Epilepsy? What would the essential objectives be? What stages would it include, and how would its results be measured?

3. How could existing materials and methodologies be used to optimal effect for these purposes?

## II. Background: some experiences

In brief, the situation with regard to academic curricula for training on epilepsy in Uruguay is as follows:

- General practitioners receive epilepsy training in:
  - ✓ Undergraduate curricula (required courses and electives);
  - ✓ Continuing medical training (epilepsy manual for primary health care (PHC) available; sessions to update PHC physicians and rural doctors).
- Graduate level specialization exists (neurology and pediatric neurology residencies).
- There is no sub-specialization in epilepsy: there is as yet no degree in epileptology.
- In late 2014, a medical diploma in clinical neurophysiology was made available.
- Training on epilepsy is provided in other, related university curricula: School of Nursing and University School of Medical Technology, specifically as part of the clinical neurophysiology program.

Experiences that have garnered the best immediate and follow-up evaluations are the elective undergraduate course on epilepsy and the curriculum for students majoring in clinical neurophysiology. In both of these cases, high levels of motivation and continuity are in evidence. At the graduate level, the subgroup of students participating in the activities that the department provides also shows high motivation and performance, in terms of attendance at regional and international courses, as well as membership in the Uruguayan League Against Epilepsy (LUCE).

A number of major challenges remain to be addressed. These include continuing to improve undergraduate and graduate training in the field of epilepsy; developing the neurophysiology degree program; developing national capacities for comprehensive training in epileptology as a sub-specialty; and including the subject in the curricula of professionals whose work significantly influences the quality of life of persons with epilepsy, such as social workers, psychologists, and primary- and secondary-level educators.

The following are examples of experiences in the Region from 2009 to 2013, provided by ILAE:

- Latin American Summer School on Epilepsy (LASSE), an annual program that, since 2007, has brought together 60 young professionals from around the Region to share their experience and receive comprehensive clinical/basic/social training from international instructors.
- “Migratory” courses and pre-convention courses organized by the Latin American Academy of Epilepsy (ALADE).

- One-year fellowships in epilepsy neurosurgery at Mexico’s National Neurology and Neurosurgery Institute, with openings for one recipient per year. The objective is to provide training in epilepsy surgery for human resources in countries that do not offer this service and lack opportunities for training in this area, with recipients being selected according to the priority that has been assigned to their country of origin.
- One-year fellowships in epileptology at various institutions in Argentina, Brazil, Chile, Colombia, and Mexico, with recipients being selected through merit-based competition and according to the priority established for the applicant’s country or origin, based on its needs. Funding support has been available for three to five fellowships per year. Recipients from Bolivia, Cuba, El Salvador, Panama, and Peru have received training, as well as participants from outlying facilities in Argentina and Colombia.
- Brief sub-specialization internships: The object is to support the creation of epilepsy facilities in the Region, by creating links with regional reference centers and providing opportunities for short (one- to three-month) internships to train these facilities’ younger staff in specific areas. In 2013, this project was conducted as a pilot, with 11 students from Bolivia, Cuba, Panama, Peru, and Uruguay.

The first generation of students finished their studies in August 2012. The main immediate results of the exchange and fellowship programs were positive; they were rated good to excellent, as measured by questionnaires that asked about satisfaction levels and included student self-evaluations.

Medium- and long-term outcomes will be measured in three areas: (a) publications; (b) medium-term professional development for graduates of LASSE; and (c) medium- and long-term evaluation of the extent to which fellowship recipients found work placements in their respective countries of origin, with periodic reports on the development of programs and services.

Based on experience, the ILAE faces a number of challenges for the future: expanding exchange and fellowship programs in Latin America; continuing to improve and update the programs; and ensuring their sustainability through international cooperation between universities. Meanwhile, it is vital to ensure that fellowship and internship recipients return to, and work in, their countries of origin.

### **III. Education component of the Strategy and Plan of Action on Epilepsy: Reflections on proposals**

The objectives of the PAHO Strategy and Plan of Action on Epilepsy are broad and general, and take in a continental perspective. They must therefore be adapted to national contexts, with clearly established priorities.

One essential proposal would be to create a regional working group to address educational objectives, with an initial minimum agenda based on: (a) evaluating regional experiences and

lessons learned; (b) studying alternatives; and (c) creating specific programs that can be offered to provide support and guidance to countries and institutions.

Collaboration with the countries to explore their educational needs and present viable alternatives for solving problems should involve national stakeholders in a more proactive way, as opposed to developing and delivering “aseptic” or “ideal” materials that each country is expected to apply dogmatically.

A general scheme of work, by stages, could be envisioned as follows:

1. Create a Regional Task Force with specialists who enjoy a high level of recognition, are representative, and have a capacity for participating in exchanges, as well as a willingness to provide in-person and online advice.
2. Collect existing information on experiences and materials within and beyond the Region, attempting to combine perceptions of the problem from the local, national, and regional perspectives.
3. Develop a range of complete educational proposals. These should include objectives, target population, form of organization, adapted educational methodology and materials, and indicators for evaluation.
4. Provide access to digitized, virtual, and printed materials and programs. Prepare virtual platforms.
5. Negotiate implementation with PAHO, ILAE, and IBE, as well as with other potential partner institutions (such as universities and PAHO/WHO Collaborating Centers).
6. Invite the participation of countries, organizations, and institutions. Supply and disseminate the proposed educational programs.
7. Evaluate the results of the educational program at the regional level, using previously defined indicators.
8. Offer the countries advice, support, and specific alternatives, where relevant, for creating their own national education programs.

#### **IV. Availability of programmatic and educational materials**

The proposed line of action would call for developing a database reflecting the different areas of the PAHO action plan, such as national plans, prevention programs, research reports, etc.

The educational component (Strategic Area 3) should include links to:

- A folder for continuing medical education, with primary care guidelines, areas of consensus, models, and didactic presentations, as well as national and international reference documents, to which PAHO, ILAE, and IBE can make a valuable contribution.

- A folder for teachers and universities, with options for undergraduate, graduate, and specialized study, elective courses, etc., as well as guidelines for the creation and management of graduate and continuing education courses (with requested cooperation from universities and reference centers).
- A folder for the general public, with subfolders for specific groups, such as children, adolescents, patients, and family members. This folder would include educational material as well as various existing national materials and videos.

## V. Proposed information platforms

Teachers generally use virtual resources to: (a) improve communication; (b) access information sources; (c) supplement or reinforce traditional teaching; and (d) develop new teaching modalities such as online courses (1).

We propose improving the use of virtual resources for educational activities in the field of epilepsy. Additional alternatives include:

- Creating a virtual library;
- Creating forums;
- Developing online self-learning courses, including programs with exercises and self-evaluation for different stages of education;
- Developing teaching materials and methodologies (presentations, videos, technical documentation, etc.); and
- Providing virtual courses in Spanish and Portuguese. In the last few years, ILAE has developed virtual courses on epilepsy on its Virtual Epilepsy Academy (VIREPA) platform. They are in English and are provided for small groups. They are demanding, and include interaction with teachers and personalized evaluation, as well as individualized feedback. They include courses on different specific subjects (electroencephalography, neuroimaging, pharmacology, etc.) are very successful, and provide excellent training for specialized professionals. However, they are costly. The Education Committee of ILAE is currently working with the Medical School of the University of the Republic (Uruguay) to develop, as a pilot project, a virtual course on epilepsy for primary care physicians in Latin America. It is in Spanish, with co-tutoring in Portuguese, and the cost is low.

## VI. Evaluating short-, medium-, and long-term results: Impact

Different types of measures and indicators can be defined to assess health policies and health education activities (2).

Measurements by time period:



- Measurement of immediate results: satisfaction/evaluation of learning by health professional immediately after finishing the educational cycle.
- Measurement of short-term results: evaluating care practice through indicators (diagnostic accuracy and case management, reduced insecurity and variability in decision-making, etc.) on a deferred basis (minimum three to six months after completion of the educational activity).
- Measuring medium-/long-term results:
  - ✓ Indicators of user satisfaction and effect of treatment on quality of life.
  - ✓ Periodic epidemiological assessments over the long term, measuring incidence, prevalence, and treatment gap.

Clear indicators to measure results must be defined, and they must be capable of being adapted to the implementation conditions in each country. Planning for the indicators should involve the various stakeholders (3):

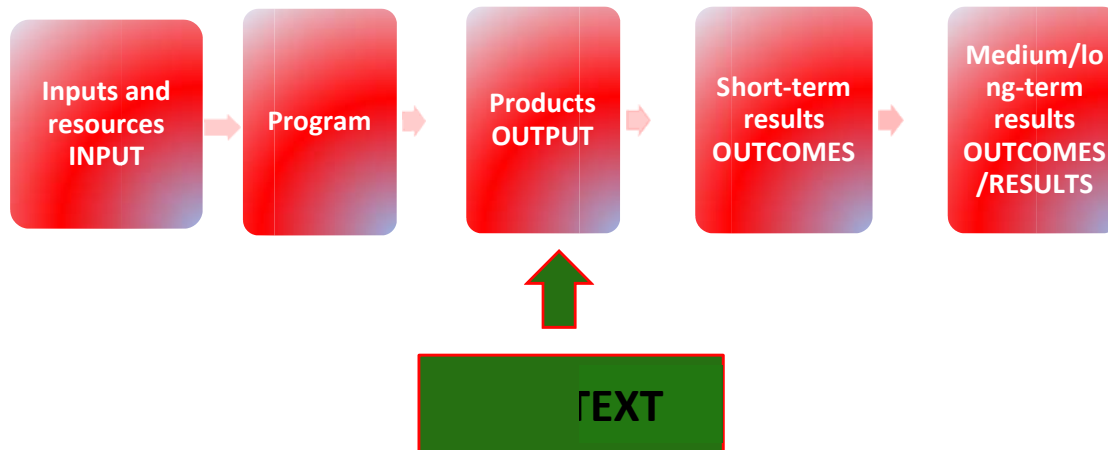
- Prospective recipients of the assistance: What are the priority changes for beneficiaries? How can they be translated into indicators?
- Intermediaries of current or future policy: Who are they and what are their lines of work and/or conflicts of interest? For decision-making and action, who needs to know what?

Evaluation makes sense only if it is used for decision-making. Evaluating the impact of an educational undertaking is a challenge (3, 4). The Development Assistance Committee (DAC) has defined impact as “the positive or negative primary and secondary long-term effects produced directly or indirectly by an intervention, intentionally or not.” (5)

In the education process, all stages and indicators will be influenced by context; thus, total replicability can never be guaranteed. The evaluation of health education programs should be participatory, with the end beneficiary contributing to the evaluation. The evaluation should be results-based, and the real impact should be measured based on improvements in the population’s health status.

Demonstration projects relating to epilepsy should, as a rule, include an education component, with specific impact evaluations for experimental or quasi-experimental designs.

**Diagram of the Jones et al. (1995) logical model to evaluate the impact of educational programs.\***



\*Figure adapted from McLaughlin JA and Jordan GB (6).

## **VII. Conclusions**

- The objective of academic training in epilepsy is to teach health personnel how to prevent, diagnose, treat, and if possible cure the disease, while improving patients' quality of life.
- It should include actors from all levels of the health system, and, ideally, personnel from other related professional areas.
- The last decade has seen significant advances in the strategies and scope of epilepsy education in Latin America, with regional initiatives playing an active role.
- Each country should define its deficiencies and priorities, as well as its ways of conducting evaluations, in light of its individual realities.
- Evaluating the impact of educational activities and strategies on patient wellbeing remains a challenge to be addressed.

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## XI

### TAENIASIS/CYSTICERCOSIS DUE TO TAENIA SOLIUM: ACCIDENTAL GUEST AND EPILEPSY PREVENTION<sup>7</sup>

Communicable Diseases and Health Analysis Department  
Neglected, Tropical and Vector Borne Diseases Unit  
Epidemic Alert and Response, and Water Borne Diseases Unit

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#### I. Introduction

1. Taeniasis and neurocysticercosis (NCC) are poverty-related diseases caused by the *Taenia solium* parasite in its adult and larval form, respectively. Poor hygiene, deficient sanitation, and agricultural use of untreated or insufficiently treated sewage facilitate their propagation.
2. The intestines of individuals with taeniasis harbor the adult form of the *T. solium*, and sufferers daily eliminate enormous quantities of the parasite's eggs in feces (as much as 80,000 eggs daily). The eggs can live up to three months in moist soil, and when the infected person defecates in the open air, the environment is contaminated, affecting crops in the vicinity. When people then eat the contaminated vegetables without washing them, they ingest the eggs, which hatch inside the human body. The larvae in turn can migrate to different parts of the body, including the subcutaneous fatty tissue, striated muscle, eyes, and even the central nervous system, where they cause NCC. This is a potentially fatal disease whose symptoms include epilepsy, intense cephalaea, and in some cases blindness.
3. In addition, the eggs of *T. solium*, if ingested by pigs, infect the intestine, where the embryo is released and passes through the intestinal wall, moving through the blood to the muscular tissues, where the larval form establishes itself, causing the disease known as cysticercosis. Cysticerci can live for several years in the animal's muscle tissue, and if a human being eats infested pork that is not well cooked, the adult form of the parasite develops in the small intestine of the person.
4. Thus, if a person is infected with *T. solium* from eating contaminated pork, taeniasis develops. If the person eats other contaminated foods, such as vegetables, containing *T. solium* eggs, or is infected via the feco-oral route, cysticercosis develops.

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<sup>7</sup> Paper presented by Dr. Enrique Pérez, PAHO Senior Advisor in Foodborne and Zoonotic Diseases, at the Regional Epilepsy Workshop in Tegucigalpa, Honduras, on 5-6 August 2015.

## II. Mandates

1. In 2011, the WHO Strategic and Technical Advisory Group on Neglected Tropical Diseases developed a roadmap for control of the 17 neglected tropical diseases, which include the *T. solium* diseases.
2. The roadmap was ratified by the Member States at the Sixty-sixth World Health Assembly (in May 2013) via Resolution WHA66.12. It emphasizes creating a validated strategy for the control of *T. solium* by 2015, and obtaining results from its implementation in various countries (to be selected), through 2020.
3. At the PAHO Directing Council (CD49.R19) and the World Health Assembly (WHA 68.20), the Member States approved measures to control and eliminate the neglected diseases and other poverty-related infections and measures to implement coordinated actions to control epilepsy, respectively.

## III. Rationale

1. It is estimated that one third of epilepsy cases in Latin America are caused by NCC (O'Neal, 2014).
2. The annual incidence of epilepsy in Latin America and the Caribbean is between 78 and 190 cases per 100,000 inhabitants (Senanayake and Roman, 1993; Burneo et al., 2005).
3. In Mexico, 144,433 individuals are estimated to suffer from epilepsy associated with NCC, while 98,520 are estimated to suffer from chronic headache due to NCC, causing an annual loss of 25,341 DALYs (disability adjusted life years) (Bhatarai 2012, *Estimating the non-monetary burden of NCC in Mexico*).
4. Today we have better knowledge, new diagnostic tools, and therapies that are safe and efficacious against the adult form of *T. solium* (namely, the anti-helminthic drugs for human use: albendazole, praziquantel, and niclosamide) and a very effective antiparasitic for pigs (oxfendazole) (Pawlowski, 2006; O'Neal, 2011). New technologies will no doubt emerge in the future. Meantime, provided there are dedicated health leaders capable of involving the entire community in the fight against *T. solium*, the existing methods are sufficient to eliminate the disease over large areas.
5. The interventions that this protocol proposes would help intensify the control of taeniasis and NCC caused by *T. solium* in endemic countries or localities. Collaboration with veterinary authorities, officials responsible for food safety, and other sectors will be essential to achieve long-term reduction in the disease burden of *T. solium*.

## IV. The protocol

1. This protocol has been developed to advance the fight against *T. solium* in endemic countries of Latin America and the Caribbean. It includes essential and effective control measures that employ simple, cost-effective tools that can be implemented by the

community itself, and by local health workers. Thus, the protocol has avoided interventions that require routine use of complex laboratory techniques, and has attempted to propose the minimum number of interventions needed to achieve an effective impact. The proposed intersectoral strategy to prevent and control *T. solium* infection will be implemented in a previously selected endemic area for a six-year period.

2. Expected results: 80% or greater reduction of *T. solium* transmission in six years, with data from year one serving as the baseline, and with 20% or greater yearly reduction of the disease burden.
3. Proposed strategic actions and interventions to obtain these results in the identified at-risk areas:
  - a. Implement a health education chain to promote changes in behavioral habits in the community, leading specifically to: confining free-ranging pigs, using latrines, and improving the handling of food products and hygiene in the home;
  - b. Periodically deworm the human population at risk;
  - c. Improve the hygiene and sanitation system; and
  - d. Implement health measures in the veterinary sector, including: periodic deworming of pigs, better veterinary inspection in slaughterhouses, and penalties for clandestine marketing networks.

## XII IN CONCLUSION: CHALLENGES AND OPPORTUNITIES

Editors

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Epilepsy is recognized as one of the most common neurological disorders at the global level. However, it is poorly understood, and is feared, hidden, and stigmatized. There are 50 million people with epilepsy in the world, 85% of whom live in developing countries. Between 60% and 90% of epileptics in developing countries do not receive appropriate treatment. Epilepsy is not a supernatural, mental, or psychological problem; it is a treatable neurological disease. Indeed, between 70% and 80% of persons with epilepsy can lead normal lives if they receive proper treatment.

The 2013 PAHO-ILAE-IBE report on programs, resources, and services related to care for persons with epilepsy in LAC countries<sup>8</sup> identifies key facts, including the following:

- Approximately two thirds of the countries in the Region lack a plan of action for epilepsy, and 80% lack legislation on the disease.
- The movement of users and families is weak in most countries.
- 87% of the countries report having facilities or services devoted specifically to epilepsy, or to neurology, with epilepsy care included. There are 94 surgical facilities treating epilepsy cases in 16 of the 25 countries analyzed in this report.
- The four basic antiepileptic drugs are included in the essential drug lists of nearly all of the countries; however, this does not mean that they are always available throughout the national territory.
- The distribution of services and human and technological resources for epilepsy care is uneven and inequitable. In some countries, the coverage that the public sector is able to provide is limited, and private services are costly, making them inaccessible to the great majority of people.
- Only one third of the countries reported that they have a regular program for training/continuing medical education on epilepsy that is targeted to health care workers.
- One third of the countries have no system to collect basic data on epilepsy through national health information systems.

Following are some important elements from the previous chapters of this technical document:

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<sup>8</sup> PAHO-ILAE-IBE. Report on Epilepsy in Latin America and the Caribbean. Washington, DC: PAHO; 2013 [accessed 29 May 2015]. Available at: [http://www.paho.org/hq/index.php?option=com\\_content&view=article&id=935&Itemid=1106&lang=en](http://www.paho.org/hq/index.php?option=com_content&view=article&id=935&Itemid=1106&lang=en)

- The epidemiology studies conducted in Honduras starting in 2000 indicate a medium level of epilepsy prevalence, ranging from 6.6 to 15.4 per 100,000 inhabitants. However, around half of persons with epilepsy are not receiving treatment from health services.
- A study in a rural area of Honduras indicates that one third of epilepsy cases are caused by NCC.
- Research-and-action projects in Honduras show that comprehensive programs that include community education can reduce the treatment gap.
- Chile is a major model for the Region. It has had a National Epilepsy Plan since 2002. Currently the Universal Plan of Health Guarantees (GES) benefits all Chileans affiliated with a public or private health care provider, guaranteeing access, timely care, financial protection, and quality of care. Epilepsy was included in the GES in 2005, as one of the country's designated 25 high-priority pathologies.
- Chile also brought its experience to bear in developing clinical practice guidelines, which were produced by working groups composed of experts from various institutions (Ministry of Health, scientific associations, and NGOs). The collaboration of a range of organizations has helped ensure quality and consensus, while reducing costs.
- Mexico's Epilepsy Priority Program (PPE) was created in October of 1984 to regulate, coordinate, systematize, and optimize actions to provide better care for persons with epilepsy. The PPE has created 65 Comprehensive Epilepsy Care Centers (CAIEs), which are incorporated in hospitals. An essential strategy of the PPE is to optimize the care of epilepsy sufferers and their families at the primary care level.
- In Mexico, between 7% and 8% of the population is estimated to have a neurological disorder. Neurological disorders account for 10% of hospitalizations annually. Of the neurological patients seen by the National Neurology and Neurosurgery Institute (INNN), 28% are being seen for epilepsy.
- Argentina and Colombia provide examples of legislation relating to epilepsy, and their experiences highlight the complexity and difficulty involved in such legislation. Moreover, it is not enough to have a law; the true challenge is in the associated regulations, and in making the law operational.
- Uruguay contributes various experiences in education, which include addressing and motivating university students through electives, conducting epilepsy research, and providing scholarships abroad.
- ILAE reports progress in graduate education for medical professionals: the Latin American Summer School on Epilepsy (LASSE); courses given by ALADE; epilepsy neurosurgery fellowships (a year at Mexico's INNN); epilepsy fellowships (providing a year at one of various facilities in Argentina, Brazil, Chile, Colombia, and Mexico); and short sub-specialty internships. First-generation fellowship recipients finished their programs in August 2012. The results of the exchange and fellowship programs have been positive.
- The E-Jaguar website is a Brazilian initiative currently in development. Its scope is regional; its object is to strengthen scientific communication for the general population, and to combat misinformation.



- In terms of technical cooperation, PAHO has promoted implementation of the GI-mhGAP Intervention Guide and Epilepsy Module as a strategy for strengthening primary health care. The process has been successful in a number of countries.

As can be inferred from the elements listed above, there are both great challenges facing Latin America and the Caribbean, as well as clear opportunities, while experience demonstrates the viability and success of numerous strategies and interventions. In conclusion, the following thoughts and recommendations are offered:<sup>9</sup>

1. The objectives of PAHO's Strategy and Plan of Action on Epilepsy are broad and general, conceived from a regional perspective; they therefore need to be adapted to individual national contexts. Implementation will require planning and sustained efforts involving all relevant stakeholders.
2. It is of priority importance to establish national programs to provide care for persons with epilepsy. Such programs should be properly incorporated in the organizational structure of health ministries, and should have the resources needed to meet the established objectives. Interventions should be based on existing realities, should take maximum advantage of available resources and previous experiences, and should have targets with measurable indicators.
3. It is important for program strategy to:
  - a. identify the factors affecting the treatment gap, in order to implement effective measures to reduce it;
  - b. improve the level of problem-solving at the primary care level, in order to promote early diagnosis and proper management of epilepsy cases; and
  - c. insure adequate coverage and equitable distribution of specialized services and technological resources.
4. Actual availability of the basic AEDs in primary care is crucial. It is recommended that the countries make use of PAHO's Strategic Fund for medicines. Information should be disseminated on this procurement mechanism, and links should be established with national authorities to promote its use.
5. Clinical practice guidelines provide guidance and direction for primary health care workers. The Epilepsy Module of the GI-mhGAP Intervention Guide and the complementary teaching materials are excellent tools based on scientific evidence and produced by WHO, with support from a high-level group of experts. The countries are urged to adapt and use it.
6. Countries are urged to support and promote passage and effective implementation of legislative instruments and legal regulations relating to epilepsy. While some countries may pass laws on epilepsy, others adopt alternative measures that make use of existing legal frameworks. The objective is to guarantee timely, high-quality health care for persons with epilepsy, and to protect their rights. It is recommended that data on

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<sup>9</sup> These final considerations are aligned with the conclusions and recommendations of the epilepsy workshop held in Honduras in August 2015.

essential points to be considered in drafting laws or legal frameworks to protect epileptics be compiled and documented.

7. The field of epilepsy-related education is a broad one. Already existing educational and training and continuing education materials on epilepsy in the Region should be reviewed and assessed, and their organized, consensus-based use should be promoted. It is also important to expand and consolidate the program of fellowships, exchanges, and internships that ILAE has been developing.
8. There are clear weaknesses in coverage of epilepsy in the undergraduate training curriculum for physicians and other health professionals and technicians, as well as in neurology residencies. A regional proposal for a curricular frame of reference needs to be developed.
9. The use of information technology in the field of epilepsy should be promoted and a community of practice developed. Scientific communication is a crucial tool for educating the lay public about epilepsy.
10. The role of civil society should be strengthened. This includes developing national ILAE and IBE chapters.
11. The role of the WHO Collaborating Center in Chile and the future Collaborating Center in Honduras (which is awaiting WHO designation) should be strengthened. These can be an important source of support for PAHO/WHO technical cooperation in the Region.
12. It is recommended that a regional working group be created (with various task-specific subgroups) to address a minimum initial agenda that includes : (a) evaluating experiences and lessons learned; (b) promoting specific initiatives to provide support for countries and institutions; and (c) creating proposals on thematic areas such as continuing education, undergraduate training, educating the public, developing programs and legislation, etc.



PAN AMERICAN HEALTH ORGANIZATION  
WORLD HEALTH ORGANIZATION



**51st DIRECTING COUNCIL**  
**63rd SESSION OF THE REGIONAL COMMITTEE**

*Washington, D.C., USA, 26-30 September 2011*

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CD51.R8 (Eng.)  
ORIGINAL: SPANISH

***RESOLUTION***

***CD51.R8***

**STRATEGY AND PLAN OF ACTION ON EPILEPSY**

***THE 51st DIRECTING COUNCIL,***

Having reviewed the *Strategy and Plan of Action on Epilepsy* (Document CD51/10);

Recognizing the burden that epilepsy represents globally and particularly in the Region of the Americas in terms of morbidity, mortality, and disability, as well as the gap between the number of people with this disorder and those who receive no treatment;

Understanding that this is an important public health problem whose prevention, treatment, and rehabilitation are feasible through specific evidence-based measures;

Considering the context and justification for action offered by the Health Agenda for the Americas 2008-2017, the PAHO Strategic Plan 2008-2012, the World Health Organization (WHO) Mental Health Gap Action Program: Scaling up care for mental, neurological, and substance use disorders (mhGAP), and the Global Campaign against Epilepsy: Out of the Shadows;

Observing that the Strategy and the Plan of Action on Epilepsy address the principal work areas and define technical cooperation lines to meet the different needs of the countries,

***RESOLVES:***

1. To endorse the Strategy and approve the Plan of Action on Epilepsy and their implementation under the particular conditions of each country to provide an appropriate response to current and future needs.
2. To urge the Member States to:
  - (a) make epilepsy a priority in national health policy by executing specific national programs suited to the conditions of each country, to sustain achievements and make progress toward meeting new goals, especially in relation to reducing the existing treatment gaps;
  - (b) strengthen legal frameworks as appropriate in order to protect the human rights of people with epilepsy and ensure effective enforcement of the laws;
  - (c) promote universal equitable access to medical care for all people with epilepsy by strengthening health services in systems based on primary health care and integrated service networks;
  - (d) ensure the availability of the four anti-epileptic drugs considered essential for treating people with epilepsy, especially at the primary care level;
  - (e) strengthen neurology services as support for case detection and management at the primary care level, ensuring adequate distribution of the necessary auxiliary diagnostic media;
  - (f) support effective participation by the community and associations of users and family members in activities designed to secure better care for people with epilepsy;
  - (g) consider strengthening human resources as key to improving national epilepsy programs, through systematic training geared especially to personnel in primary health care;
  - (h) promote intersectoral and educational initiatives directed to the population to combat the stigma and discrimination suffered by people with epilepsy;
  - (i) close the information gap in the field of epilepsy by improving the production, analysis, and use of information, including research;
  - (j) strengthen partnerships between the health sector, other sectors, and nongovernmental organizations, academic institutions, and key social actors.

3. To request the Director to:
  - (a) assist the Member States in the preparation and execution of national epilepsy programs within the framework of their health policies, taking the Strategy and Plan of Action into account, with a view to correcting inequities and giving priority to the care of vulnerable and special needs groups, including indigenous populations;
  - (b) collaborate in the evaluation and restructuring of the countries' neurology and mental health services;
  - (c) facilitate the dissemination of information and the sharing of positive innovative experiences, and promote technical cooperation among the Member States;
  - (d) promote partnerships with the International League against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE), as well as with international agencies, governmental and nongovernmental organizations, and other regional actors in support of the broad multisectoral response needed for the execution of this Strategy and Plan of Action;
  - (e) evaluate the implementation of the Strategy and Plan of Action and report to the PAHO Directing Council in five years.

*(Seventh meeting, 29 September 2011)*



**SIXTY-EIGHTH WORLD HEALTH ASSEMBLY**  
**Provisional agenda item 13.5**

**A68/12**  
**27 March 2015**

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# **Global burden of epilepsy and the need for coordinated action at the country level to address its health, social and public knowledge implications**

## **Report by the Secretariat**

1. The Executive Board at its 136th session considered the attached document EB136/13<sup>1</sup> and adopted resolution EB136.R8.<sup>2</sup>

### **ACTION BY THE HEALTH ASSEMBLY**

2. The Health Assembly is invited to adopt the draft resolution recommended by the Executive Board in resolution EB136.R8.

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<sup>1</sup> See summary record of the 136th session of the Executive Board, thirteenth meeting and fourteenth meeting, section 1.

<sup>2</sup> See document EB136/2015/REC/1 for the resolution, and for the financial and administrative implications for the Secretariat of the adoption of the resolution.

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# **Global burden of epilepsy and the need for coordinated action at the country level to address its health, social and public knowledge implications**

## **Report by the Secretariat**

### **BURDEN AND IMPACT OF EPILEPSY**

1. Epilepsy is one of the most common serious chronic neurological diseases affecting people of all ages globally. It is characterized by recurrent seizures. It has many causes. In some cases, there is an underlying genetic basis. Other common causes of epilepsy include brain damage from prenatal or perinatal injuries (for example, a loss of oxygen or trauma during birth); congenital abnormalities or brain malformations; head injury; stroke; neurological infections, such as meningitis, encephalitis and neurocysticercosis; and brain tumour. In about half the cases of epilepsy, the cause cannot be identified.
2. More than 50 million people worldwide have epilepsy, more than three quarters living in low- and middle-income countries. An estimated 2.4 million new cases occur each year. Epilepsy accounts for 0.5% of the total global burden of disease.
3. The risk of premature death in people with epilepsy is 2–3 times higher than for the general population in high-income countries and more than six times higher in low- and middle-income countries. People with epilepsy often suffer from comorbidities such as depression and anxiety, associated intellectual disabilities, especially in children, and physical injuries (for instance, fractures and burns).
4. People with epilepsy are often subjected to stigmatization and discrimination because of misconceptions and negative attitudes surrounding the disease. Some common misconceptions are “possession by evil spirits”, “epilepsy is contagious” or its equivalence to “madness”. Stigmatization leads to human rights violations and societal exclusion. For example, in some settings children with epilepsy may not be allowed to go to school and adults may not find suitable employment or be able to marry.

5. In addition to its social implications, epilepsy results in huge economic costs. In the WHO European Region, for example, these costs have been estimated at €20 000 million per year.<sup>1</sup>

## **CHALLENGES AND GAPS IN EPILEPSY CARE**

6. Up to 75% of people with epilepsy can live a normal life, free from seizures, if they are appropriately treated with antiepileptic medicines. Treatment with first-line antiepileptic medicines (phenobarbital, phenytoin, carbamazepine and valproic acid) is among the identified “best buys” for neurological diseases with the cost of treatment with phenobarbital as low as US\$ 5 per person per year.<sup>2</sup> All the medicines are included in the WHO Model List of Essential Medicines.

7. Despite the availability of affordable treatment, up to 90% of people with epilepsy may not be properly diagnosed or treated in resource-poor settings. The so-called “treatment gap” (the percentage of people with epilepsy whose seizures are not being appropriately treated at a given point in time) is estimated to be 75% in low-income countries and substantially higher in rural areas than in urban areas.

8. Such a wide treatment gap may result from a combination of, for instance, inadequate capacities of health care systems and inequitable distributions of resources, particularly in resource-poor and rural areas. Factors that widen the gap, many of which are interconnected, include an insufficiency of staff, poor access to antiepileptic medicines, societal ignorance and misconceptions, poverty, and low prioritization for the treatment of epilepsy.

9. Only limited numbers of specialist health professionals are available in low- and middle-income countries; for example, the median number of neurologists in low-income countries is only 0.03/100 000 population. Epilepsy can be treated at primary health care level but very often the health care workers there are not adequately trained to diagnose or treat epilepsy.

10. Many barriers to accessing antiepileptic medicines exist. The price often remains unjustifiably high, even for generic medicines. Data and information necessary for planning, forecasting and budgeting are often lacking. Certain regulatory policies prevent wider use of some antiepileptic medicines, particularly those associated with the procurement of phenobarbital. Although national essential medicines lists frequently include first-line antiepileptic medicines, their inclusion does not guarantee availability in public health care facilities.

11. An analysis of availability, price and affordability of antiepileptic medicines in public hospitals and primary health care facilities from surveys in 46 Member States estimated the average availability of generic oral antiepileptic medicines as less than 50%. Prices charged to patients in the public sector for generic carbamazepine and phenytoin were 4.95 and 17.50 times higher than international reference prices, respectively. The lowest-paid government worker in the countries surveyed would

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<sup>1</sup> International League Against Epilepsy, International Bureau for Epilepsy, World Health Organization. Global campaign against Epilepsy. Epilepsy in the WHO European Region: fostering epilepsy care in Europe. Hoofddorp, The Netherlands: Global Campaign Against Epilepsy, 2010 (see [http://www.who.int/mental\\_health/neurology/epilepsy/euro\\_report.pdf?ua=1](http://www.who.int/mental_health/neurology/epilepsy/euro_report.pdf?ua=1), accessed 24 November 2014).

<sup>2</sup> Abegunde D. Essential medicines for non-communicable diseases: background paper. Geneva: World Health Organization ([http://www.who.int/medicines/areas/policy/access\\_noncommunicable/EssentialMedicinesforNCDs.pdf](http://www.who.int/medicines/areas/policy/access_noncommunicable/EssentialMedicinesforNCDs.pdf), accessed 24 November 2014).



spend between 1.1 and 2.6 days' wages to buy a month's supply of phenytoin; the comparable figure for carbamazepine was between 2.7 and 16.2 days' wages.<sup>1</sup>

12. Lack of knowledge or misperceptions about epilepsy may affect health-seeking behaviour. People with epilepsy may not access treatment from health care facilities and instead might seek help from other sources that may be ineffective. They also may not seek regular follow-up care or adhere to medications as prescribed.

## INTERNATIONAL CONTEXT AND THE SECRETARIAT'S ACTIVITIES

13. In 2003, the Health Assembly noted the report on the control of neurocysticercosis with its references to epilepsy,<sup>2</sup> and, in resolution WHA66.8 in May 2013, it adopted the comprehensive mental health action plan 2013–2020, which builds on the work of WHO's mental health gap action programme and notes that actions taken to promote mental health and prevent mental disorders are relevant for the prevention of epilepsy and other neurological disorders. Other resolutions are also pertinent to coordinated action on epilepsy include United Nations General Assembly resolution 66/2 adopting the Political Declaration of the High-level Meeting of the General Assembly on the Prevention and Control of Non-communicable Diseases, the Health Assembly's resolution WHA66.10 which endorsed the global action plan for the prevention and control of noncommunicable diseases 2013–2020, resolutions 68/269 and WHA57.10 on road safety, resolution WHA66.12 on neglected tropical diseases, resolution WHA67.10 on newborn care and resolution WHA67.15 on violence.

14. In 1997, WHO and two international nongovernmental organizations, the International League Against Epilepsy and the International Bureau for Epilepsy, launched the *Global Campaign Against Epilepsy: Out of the Shadows* in order to raise awareness and strengthen efforts to improve care and reduce the impact of epilepsy. Under the auspices of the global campaign, demonstration projects have been undertaken in Argentina, Bolivia (Plurinational State of), Brazil, China, Georgia, Pakistan, Senegal, Timor-Leste and Zimbabwe. For example, the project in China was implemented in six provinces between 2000 and 2004 to test the feasibility of diagnosis and treatment of epilepsy at the primary health care level. The results showed that trained primary health care physicians could diagnose and treat people with epilepsy, and that the care model could significantly reduce the epilepsy treatment gap.<sup>3</sup> This project has been extended to 18 provinces and covers a population of 75 million.

15. In 2005, WHO published a compilation of relevant information about resources for care of mental and neurological conditions in the world.<sup>4</sup> The publication emphasized that globally the available resources for epilepsy care are insufficient for the large number of people needing such care and the known substantial burden associated with the disease. In addition, large inequities exist across regions and income groups of countries, with low-income countries having extremely meagre resources.

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<sup>1</sup> Cameron A, Bansal A, Dua T, Hill SR, Moshe SL, Mantel-Teeuwisse AK et al. Mapping the availability, price, and affordability of antiepileptic drugs in 46 countries. *Epilepsia*, 2012; 53:962–969.

<sup>2</sup> See document WHA56/2003/REC/3, summary record of the fourth meeting of Committee A.

<sup>3</sup> Epilepsy management at primary health level in rural China: WHO, International League Against Epilepsy, International Bureau for Epilepsy. Geneva: World Health Organization; 2009.

<sup>4</sup> WHO, International Bureau for Epilepsy, International League Against Epilepsy. Atlas: epilepsy care in the world 2005. Geneva: World Health organization; 2005.

16. In 2008, WHO launched the WHO Mental Health Gap Action Programme, which includes epilepsy as a priority mental health and neurological condition. The Programme's objective is to expand services for mental, neurological and substance use disorders in low- and middle-income countries using an innovative and multifaceted approach. The Secretariat has issued normative materials such as the Programme's intervention guide for mental, neurological and substance use disorders in non-specialized health settings and related training materials, which cover epilepsy care management.<sup>1</sup>

17. The WHO Programme on Reducing the Epilepsy Treatment Gap builds on the experience with non-specialist primary health care providers to diagnose, treat and follow up people with epilepsy. It also mobilizes nongovernmental organizations and community groups among others to raise awareness about epilepsy and support people with epilepsy and their families, and supports health system strengthening to ensure sustainable access to antiepileptic medicines, reinforce referral systems, and enable better monitoring of epilepsy. Pilot initiatives have been initiated in Ghana, Mozambique, Myanmar and Viet Nam.<sup>2</sup>

18. Regional conferences on public health aspects of epilepsy have been organized in all six WHO regions, with the participation of some 1300 delegates from more than 90 countries. Regional reports on epilepsy and declarations have also been issued by different WHO regions. The regional reports emphasize the need for action on public education, legislative reform, investment in research, support for organizations or associations on epilepsy, information exchange, and community-based control and prevention programmes.<sup>3</sup>

19. In 2011, the Region of the Americas approved and has subsequently been implementing the Strategy and Plan of Action on Epilepsy for 2012–2021.<sup>4</sup> The strategy defines priority areas for epilepsy, including the need to promote programmes and legislation for the care of people with epilepsy and the protection of their human rights; establish networks of health services for people with epilepsy, with emphasis on primary health care and the provision of antiepileptic medicines; educate and sensitize the general population, including people with epilepsy and their families; and strengthen the ability to produce, assess and use information on epilepsy.

20. Also in 2011, the European Parliament approved the written declaration on epilepsy.<sup>5</sup> The declaration calls for the European Commission and Council to encourage research and innovation in the area of prevention and early diagnosis and treatment of epilepsy; prioritize epilepsy as a major disease that imposes a significant burden across Europe; encourage measures to ensure equal quality of life, including access to education, employment, transport and public health care for people with epilepsy, for instance by stimulating the exchange of best practice; and encourage effective health

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<sup>1</sup> mhGAP intervention guide for mental, neurological and substance use disorders in non-specialized health settings, available at [http://www.who.int/mental\\_health/publications/mhGAP\\_intervention\\_guide/en/](http://www.who.int/mental_health/publications/mhGAP_intervention_guide/en/) (accessed 21 November 2014).

<sup>2</sup> [http://www.who.int/mental\\_health/neurology/epilepsy/en/](http://www.who.int/mental_health/neurology/epilepsy/en/).

<sup>3</sup> For links to regional reports and declarations, see [http://www.who.int/mental\\_health/publications/epilepsy\\_neurological\\_disorders/en/](http://www.who.int/mental_health/publications/epilepsy_neurological_disorders/en/) (accessed 21 November 2014).

<sup>4</sup> See resolution CD51.R8 and document CD51/10: [http://www.paho.org/hq/index.php?option=com\\_docman&task=doc\\_download&gid=24657&Itemid=270&lang=en](http://www.paho.org/hq/index.php?option=com_docman&task=doc_download&gid=24657&Itemid=270&lang=en) (accessed 21 November 2014).

<sup>5</sup> European Parliament. Written declaration on epilepsy. Brussels, European Parliament, 0022/2011, 2011 (<http://www.ilae.org/Visitors/initiatives/documents/writtendeclaration.pdf>, accessed 21 November 2014).

impact assessments on all major European and national policies. It calls on Member States of the European Union to introduce appropriate legislation to protect the rights of all people with epilepsy.

## **IMPROVING EPILEPSY CARE: WHAT IS NEEDED**

21. Several actions can be taken at country level to make progress in dealing with the global public health issue of improving epilepsy care. These are outlined in paragraphs 22–30 below.

22. **Strengthen effective leadership and governance.** National policies and legislation need to be formulated, strengthened and implemented in order to promote and protect rights of people with epilepsy and to prohibit discrimination in, for example, education, employment, marriage, reproduction, driving regulations and recreation.

23. **Improve provision of epilepsy care.** Policies on general health, mental health or noncommunicable diseases should include consideration of care for people with epilepsy. Budgets should be allocated that are commensurate with the human and other resources that have been identified as necessary to implement agreed-upon evidence-based plans and actions. Stakeholders from all relevant sectors, including people with epilepsy and their carers and family members, should be engaged in the development and implementation of policies, laws and services.

24. **Integrate epilepsy management into primary health care.** In order to help to reduce the epilepsy treatment gap, non-specialist health care providers should be trained and supported so that epilepsy can be diagnosed and treated in primary health care settings. A strong and functional referral system should be made available.

25. **Increase access to medicines.** Strategies should be formulated and implemented to make antiepileptic medicines more available, accessible and affordable. Strategic options are: to include essential antiepileptic medicines in national formularies; to strengthen supply chains and systems of selection, procurement and distribution; and to improve access to controlled medicines such as phenobarbital. It is estimated that extending the coverage of treatment with antiepileptic medicines to 50% of epilepsy cases would reduce the current epilepsy burden by between 13% and 40%.

26. **Support strategies for prevention of epilepsy.** Many of the causes of epilepsy in low- and middle-income countries are preventable, and the health and social sectors should be supported to assist in reducing the incidence of epilepsy. Effective implementation of relevant United Nations General Assembly and Health Assembly resolutions (see paragraph 13 above) could help to prevent many cases of epilepsy. Examples include promoting safe pregnancies and births, control of cysticercosis, prevention of head trauma, and prevention of stroke.

27. **Increase public awareness and education.** In order to help to reduce misconceptions and negative attitudes, and to influence more people with epilepsy to seek treatment, public education activities related to epilepsy should be strengthened, and community leaders, grassroots public health workers, and people with epilepsy and their families should be educated about the disease. The Secretariat should provide support to Member States in harnessing the potential contribution of traditional medicine to the health and well-being of people with epilepsy. These actions should help to reduce stigmatization of and discrimination against people with epilepsy.

28. **Strengthen health information and surveillance systems.** Data on epilepsy should be captured, collated, routinely reported, analysed and disaggregated by sex and age in order to measure progress in increasing access to services for people with epilepsy. National data systems and exchange

of information between countries should also be reinforced, for instance collaboration on data collection.

29. **Improve investment in epilepsy research and increase research capacity.** Surveillance should be improved and comprehensive, accurate epidemiological estimates made of the burden of epilepsy, particularly in low- and middle-income countries. Informed and effective decision-making should be facilitated through the development of standardized and validated research tools. In addition to epidemiological research, priority should be given to research areas such as genetics; health system evaluation; diagnostics, prevention, treatment and rehabilitation; and scientific investigation of traditional medicine approaches to epilepsy treatment. The research capacity of low- and middle-income countries should be built through expanded academic collaboration and establishing centres of excellence in such countries.

30. **Collaborate with civil society and other partners.** National epilepsy-related organizations should be established in order to improve care for people with epilepsy and to strengthen advocacy. These bodies could include professional societies, charitable foundations, epilepsy centres, and associations of patients and their families.

#### **ACTION BY THE EXECUTIVE BOARD**

31. The Board is invited to take note of the report and provide further guidance on the need for a coordinated action at the country level to address the health, social and public knowledge implications of the global burden of epilepsy.

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**ANNEX 3**  
**EPILEPSY IN LATIN AMERICA: PROGRESS AND CHALLENGES**  
**WORKSHOP**

**Date:** 5-6 August 2015  
**Workshop held at:** Medical School of Honduras, Auditorium  
**Organized by:** Pan American Health Organization (PAHO/WHO)  
School of Medicine, National Autonomous University of Honduras

**Objectives:**

1. Discuss successful experiences, progress, and lessons learned in selected countries of Latin America, within the framework of implementation of the Strategy and Plan of Action on Epilepsy.
2. Analyze challenges and opportunities with a view to the future.

**WORKSHOP REPORT**

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*Wednesday, 5 August 2015*

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Opening remarks were given by Dr. Marco Medina, Dean of the School of Medicine, National Autonomous University of Honduras; Ana Treasure, PAHO/WHO Representative in Honduras; and Dr. Francis Contreras, Undersecretary of Health.

The opening speech, “Epilepsy and Mental Health in Primary Care”, was given by Dr. Francis Contreras, Undersecretary of Health, who briefly described the epidemiological situation of epilepsy in Honduras, based on studies by the School of Medicine of the National Autonomous University of Honduras. More than half of identified epilepsy cases were caused either by neurocysticercosis or traumatic injuries related to childbirth, both of which are preventable. In this regard, he emphasized the efforts made by the Ministry of Health to develop decentralized maternal and child health centers and guarantee better conditions of care during delivery. With regard to nervous system infections (cysticercosis), the Undersecretary described the interventions carried out in communities and schools with special emphasis on measures to break the cycle of transmission of the infection, beyond simply enclosing pigs.

The general introduction to the workshop was given by Ms. Dévora Kestel, Chief of the PAHO/WHO Mental Health and Substance Use Unit.

Dr. Jorge Rodríguez, Mental Health Consultant, presented the technical document that served as a basis and frame of reference for the workshop. This document, which contains the highlights of the regional workshop held in Chile in August 2013, will be available in the Mental Health section of the PAHO/WHO website.

A panel discussion on “Epidemiology of epilepsy and a program to bridge the treatment gap in Honduras” was coordinated by Dr. Lázaro Molina, with panelists from the neurology team at the School of Medicine, National Autonomous University of Honduras.

Country experiences were presented, followed by comments and discussion.

### ***Morning session—Coordinator: Dr. Carlos Acevedo***

The following presentations were given:

- National Epilepsy Program in Chile. Experiences of implementation. Dr. Lilian Cuadra (Chile).
- Virtual course on epilepsy developed by the Chilean League against Epilepsy and the Ministry of Health of Chile. Dr. Tomas Mesa (Chile)

### ***Afternoon session—Coordinator: Dr. Lázaro Molina***

Afternoon presentations:

- Priority Program on Epilepsy in Mexico: Dr. Francisco Rubio D.
- Colombia: Dr. Nubia E. Bautista
- Guatemala: Dr. Henry Stokes
- Bolivia: Dr. Walter Mario Camargo

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*Thursday 6 August, 2015*

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### ***Morning session***

Country experiences were presented by:

- Peru: Dr. Yuri Cutipe
- Cuba: Dr. Lilia Morales

A summary of the first day’s activities was presented by Dr. Carlos Acevedo (Chile) and Dr. Lázaro Molina (Honduras).

### ***Morning session (continued)—Coordinator: Dr. Fátima Valle***

The following presentations were given:

- “Taeniasis/cysticercosis caused by *Taenia solium*: Accidental host and epilepsy prevention” by Dr. Enrique Pérez, Senior Advisor on Zoonosis, PAHO/WHO.
- Presentations by invited experts:
  - ✓ Dr. Vicente Iragui-Madoz, ILAE Commission on North American Affairs: Some considerations concerning epilepsy education in Latin America.

- ✓ Dr. Samuel Wiebe, Secretary General of ILAE: A general overview of ILAE and epilepsy at the global level.
- ✓ Dr. Esper Cavalheiro, ILAE, Brazil: Educational processes in epilepsy and the summer school experience.
- “Availability and access to antiepileptic drugs (AEDs) in primary care” by Dr. Carlos Acevedo, President of the PAHO/WHO Collaborating Center in Chile, and Dr. Nora Girón, Regional Advisor on Medicines, PAHO/WHO Honduras.
- “Epilepsy: A public health vision” by Dr. Jorge Valle, Academic Secretary of the Medical School of Honduras.

### ***Afternoon session—Coordinator: Dr. Jorge Rodríguez***

#### **Open discussion on the challenges and opportunities going forward**

Participants were invited to freely comment, ask questions, and make recommendations about how to best implement the Regional Strategy on Epilepsy in order to improve the quality of life of people with that condition.

Dr. Rodríguez mentioned some key points that had been discussed during the workshop and invited participants to consider them and make specific proposals regarding education, legislation, plans and programs, and primary care. The consensus on action is summarized at the end of this report.

#### **Education and training:**

- Epilepsy education is a crucial and strategic issue.
- It is necessary to identify target groups, such as primary health care (PHC) physicians, other health workers, lobby groups, people with epilepsy and their family members, and the general public, among others. It is also important that differentiated “trainer training” be a basic element in a cascade process.
- In the Region, abundant epilepsy materials and training methods are available. These should be collected and reviewed, and proposals made for their use.
- It is necessary to avoid overlapping efforts and misuse of resources.
- Prior to continuing education, it is also crucial to improve the initial education of physicians and other health professionals and technical workers. This is a complex process that involves modifying university curricula.

**Drugs:** It is essential that AEDs are available in PHC in order to bridge the treatment gap. Four basic AEDs have been recommended for PHC. However, countries are still not using the regional mechanism of the Strategic Fund. It is necessary to step up efforts in this regard.

#### Plans and legislation:

- Implementation of the Regional Strategy on epilepsy, approved by the PAHO Member States, requires the development of national plans and legal frameworks.
- At present, only a minority of countries have plans and regulatory frameworks for epilepsy.
- Flexibility is suggested in the case of legal frameworks, with each country taking the most viable route to improving comprehensive care for people with epilepsy and protecting their rights.
- PHC is the linchpin of the strategy, with in-service training activities and linkages to the reorganization and strengthening of the health services network.

#### Other aspects discussed:

- Improve and make more efficient use of information technology.
- Integration of joint efforts to eradicate cysticercosis.
- Coordination between the two Coordinating Centers in the Region: Chile and Honduras (the latter is in the designation process).
- Opportunities for new projects and initiatives; relations with the ILAE Commission on North American Affairs.

#### Closing session

The conclusions of the workshop were presented by Ms. Dévora Kestel and Dr. Marco T. Medina, who thanked the participants and offered a positive assessment of the workshop, while emphasizing the importance of monitoring the agreements reached.

#### Agreements

- 1- Create a PAHO/ILAE/IBE working group to compile, review, and analyze the existing educational and continuing education/training material on epilepsy in the Region, in order to evaluate it and promote its organized and consensual use. Dr. Mauricio Olave (Colombia) and Dr. Alejandro Scaramelli of ILAE (ALADE) were proposed as coordinators.  
*Responsible persons/organizations:* Dr. Marco T. Medina and Dr. Tomás Mesa, and PAHO/WHO.
- 2- Prepare a draft proposal for undergraduate education on epilepsy aimed at physicians and other health professionals and technical personnel, as well as residents in neurology. Also, prepare a draft framework for an epilepsy curriculum.  
*Coordination:* School of Medicine of the National Autonomous University of Honduras.  
*Responsible persons/organizations:* Dr. Lázaro Molina.
- 3- Develop a format or template for a model epilepsy program that can be subsequently adapted to the situation in each country. This work would also be made available at the



PAHO, ILAE, IBE, and E-Jaguar websites. *Responsible persons/organizations:* Drs. Lilian Cuadra (Chile) and Lilia Morales (Cuba).

- 4- Create a working group to compile and document the key issues to be considered in the preparation of a law or legal framework to protect people with epilepsy. *Responsible persons/organizations:* Marlon Ávila, lawyer and President of the Honduran Chapter of the IBE, with the cooperation of volunteer lawyers of the Chilean League against Epilepsy (Gloria Quiero and Gabriela Silvetti), Silvia Kochen (Argentina), and Jaime Fandiño (Colombia).
- 5- Compile and disseminate all available information on the PAHO/WHO Strategic Fund, explaining how to use it and the advantages it offers to countries purchasing antiepileptic drugs. *Responsible persons/organizations:* PAHO/WHO.
- 6- Promote and facilitate the participation of professionals in the epilepsy field at the next meeting on cysticercosis to be held in Colombia, from 6 to 10 October. Participation by representatives of Honduras, Peru, and Colombia will be given particular consideration. *Responsible persons/organizations:* PAHO/WHO.
- 7- Promote the use of information technology in the epilepsy field and develop a community of practice. This task will be undertaken by the PAHO/WHO Collaborating Centers (CCs). *Responsible persons/organizations:* CCs in Chile and Honduras, with PAHO/WHO support.
- 8- Establish a mechanism for cooperation between the CC in Chile and the future CC in Honduras, which is awaiting WHO designation. Consider holding a meeting on this issue at the end of this year. *Responsible persons/organizations:* Drs. Marco T. Medina and Carlos Acevedo, with PAHO/WHO support.
- 9- The report on this workshop will be included in the technical document on experiences and advances in the field of epilepsy, and will be made available at the website in the coming weeks. *Responsible persons/organizations:* PAHO/WHO.

## List of participants

- Dévora Kestel, Unit Chief, Mental Health and Substance Use, PAHO
- Marco Tulio Medina, Dean of the Medical School of the National University of Honduras, and ILAE Vice President for Latin America
- Carlos Acevedo, Director, PAHO/WHO Collaborating Center in Chile
- Tomás Mesa, Chairman of the Chilean League against Epilepsy and Chairman of the Latin American Committee of the IBE
- Fátima Valle, National Consultant, PAHO/WHO Honduras
- Enrique Pérez, Senior Advisor on Zoonosis, PAHO/WHO
- Nora Girón, Regional Advisor on Medicines, PAHO/WHO
- Jorge Rodríguez, Mental Health Consultant
- Vicente Iragui-Madoz, ILAE Commission on North American Affairs
- Samuel Wiebe, Secretary General of ILAE
- Esper Cavalheiro, ILAE
- Lázaro Molina, Medical School of Honduras
- Jorge Valle, Medical School of Honduras

### International participants:

- Chile: Lilian Cuadra, Coordinator, Epilepsy Program, Ministry of Health
- Colombia: Nubia E. Bautista, Psychiatrist, Office of the Assistant Director for Noncommunicable Diseases, Ministry of Health
- Mexico: Francisco Rubio D., Priority Program on Epilepsy, Mexico/ILAE
- Bolivia: Walter Mario Camargo Villa Real, Bolivian Chapter of ILAE, Coordinator of Epilepsy Week in Bolivia
- Bolivia: Dennis Villarroel, Ministry of Health
- Cuba: Lilia Morales, Clinical Neurophysiologist, President of the Cuban Chapter of ILAE
- Guatemala: Henry Stokes, Honorary President of the Guatemala Chapter of ILAE
- Peru: Yuri Cutipie, Mental Health Director, Ministry of Health

### Honduran Participants:

- Claudia Avidet
- Lester José Coello
- Dennis E. Maldonado
- Alex A. Meléndez
- Martha Zelaya
- Sarahi Olivera
- Sonia M. Fajardo
- Maritza Figueroa

- Karla Boquin
- Marisela V. Irias
- Victoria G. Interino
- Ana Melissa
- Selvin Reyes
- Hebel Oziel
- Octavio Sánchez
- Heike Hesse
- Jorge Ortiz
- Patricia Ponce
- Marlon Ávila
- Alejandra Raudales



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