

# Improving the Management of Epilepsy and its Comorbidities in the Caribbean

Regional Workshop  
Trinidad and Tobago, 28 February – 1 March 2018



Improving the Management of Epilepsy and its Comorbidities in the Caribbean. Regional Workshop (Trinidad and Tobago, 28 February – 1 March 2018)  
Document Number: PAHO/NMH/18-028

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**Suggested citation.** Pan American Health Organization. Improving the Management of Epilepsy and its Comorbidities in the Caribbean. Regional Workshop (Trinidad and Tobago, 28 February – 1 March 2018). Washington, D.C.: PAHO; 2018.

**Cataloguing-in-Publication (CIP) data.** CIP data are available at <http://iris.paho.org>.

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## Table of Contents

|                         |   |
|-------------------------|---|
| Executive Summary ..... | 5 |
| Introduction.....       | 5 |
| Aim and Objectives..... | 6 |
| Agenda Overview.....    | 7 |

### Day 1:

|   |   |
|---|---|
| Epilepsy in the Americas: The Current Situation ..... | 7 |
|---|---|

#### Panel Discussion: Regional Collaboration in Epilepsy

|  |    |
|--|----|
| Regional Collaboration in Epilepsy .....                       | 8  |
| Strategy and Plan of Action on Epilepsy in the Americas.....   | 8  |
| PAHO Strategy and Plan of Action on Epilepsy .....             | 9  |
| ILAE Commission for Latin American Affairs .....               | 9  |
| Remarks from Samuel Wiebe, President.....                      | 9  |
| State of Epilepsy Care in the English-Speaking Caribbean ..... | 11 |

#### Panel Discussion: Country Experiences on Integrating Epilepsy into Pre-existing Health Programs

|   |    |
|---|----|
| Epilepsy in Barbados.....   | 11 |
| How Epilepsy Services Can Be Integrated into Pre-existing Health Programs in Jamaica .....                                  | 11 |
| Epilepsy in the Tri-Island State of Grenada .....   | 12 |
| Epilepsy Care in St. Lucia .....  | 12 |
| Epilepsy Care in Trinidad and Tobago: Moving from Chronic Diseases to Specialized Care.....                                 | 12 |
| Introduction to mhGAP Epilepsy Module.....  | 13 |
| The Role of Family and User’s Associations: Advantages and Impact on the Community: Successful Anti-stigma Initiatives..... | 13 |

#### Roundtable

|   |    |
|---|----|
| The Need for Patient Advocacy in Public Institutions: Schools and Work .....      | 13 |
| The Need for Patient Advocacy: Research, Academic Institutions and Hospitals..... | 14 |
| Epilepsy and Driving: The Caribbean Case.....                                     | 14 |

### Day 2:

|   |    |
|---|----|
| Regional and Global Commitments.....  | 15 |
| Improving the Accessibility and Affordability of Safe AEDs: An Overview of the PAHO Strategic Fund.....   | 15 |
| Barriers and Opportunities to Advance with the Commitments to Implement the PAHO Epilepsy Action Plan: The Role of Regional and National Organizations..... | 15 |

Group Work ..... 16

Follow-up and Recommendations..... 17

Annexes

A: Workshop Agenda..... 18

B: Participant List..... 21

## **Executive Summary**

The Pan American Health Organization (PAHO), in partnership with Epilepsy Society of the Caribbean (ESC), the International League Against Epilepsy (ILAE), and the International Bureau for Epilepsy (IBE), organized a regional workshop from 28 February to 1 March 2018 in Trinidad to strengthen country capacity to deliver evidence-based care to people with epilepsy within the framework of PAHO's Strategy and Plan of Action on Epilepsy.

Present for the official ceremony were Dr. Bernadette Theodore-Gandi, PAHO Representative for Trinidad and Tobago, and Chief Medical Officer, Dr. Roshan Parasram, from the Ministry of Health of Trinidad and Tobago. The workshop was attended by 29 participants, 8 of whom represented ministries of health of the following countries: Antigua and Barbuda, Barbados, Dominica, Grenada, Jamaica, St Kitts and Nevis, St Lucia, and Trinidad and Tobago. Other countries from the Region were invited but could not send representatives. Additional participants included key regional partners from the ESC, ILAE, and IBE. Participants from PAHO, at the regional and local level, were present. (For a full workshop participant list, please refer to Annex B on page 18.)

Key topics discussed during the workshop were: the midterm review of the PAHO Epilepsy Plan of Action, the state of epilepsy care in the Caribbean, the integration of epilepsy care into health programs, the PAHO Strategic Fund as a strategy to improve the accessibility and affordability of antiepileptic drugs (AEDs), and regional and global commitments. PAHO also took the opportunity to introduce the Mental Health Gap Action Programme Intervention Guide (mhGAP-IG)'s Epilepsy module. The workshop concluded with working groups addressing the four strategic lines of action of PAHO's Epilepsy Plan and making recommendations for its operationalization in the Caribbean.

Following the workshop, on Friday March 2nd, Dévora Kestel was invited to provide opening remarks at the Opening Ceremony of the 6<sup>th</sup> North American Regional Caribbean Congress on Epilepsy, also held in Trinidad and Tobago. The theme of the Congress was "The Many Faces of Seizures, Spells and Blackouts," which Mrs. Kestel addressed in her remarks in addition to PAHO's progress to date on achieving the indicators of its Strategy and Plan of Action on Epilepsy.

## **Introduction**

Epilepsy is one of the most common neurological disorders in the world. It is a disorder which affects people of all ages, countries and socioeconomic circumstances. Among those affected are not only the people with epilepsy themselves, but also their loved ones and caretakers. In our region, epilepsy affects more than 5 million people. It is estimated that up to 70% of people with epilepsy can live normal lives if they receive proper care. However, in Latin America and the Caribbean (LAC), more than half of people with epilepsy do not receive any form of medical care from health services. Furthermore, people with epilepsy can experience stigma, prejudice, and human rights abuses, which can be worse than the seizures themselves.

PAHO recognizes epilepsy as a major public health concern and is committed to cooperating with Member States as they work towards improving care and quality of life for people with epilepsy. In 2011, PAHO's 51<sup>st</sup> Directing Council approved the Strategy and Plan on Epilepsy 2012-2021 (CD51.R8), which establishes four strategic action areas: programs and legislation for the care of people with epilepsy and protection of their human rights; health services network for the treatment of people with epilepsy, with emphasis on primary health care and the provision of drugs; education and sensitization

of the population, including the people with epilepsy and their families; and strengthening of the ability to produce, assess, and use information on epilepsy.

Since 2011, PAHO has collaborated with Member States, the ILAE, the IBE, and other partners to set priorities, mobilize resources, and encourage cooperation among countries to achieve progress in these areas. Some key initiatives include the training of Primary Health Care personnel in the Epilepsy module of the mhGAP-IG, and the convening of two international workshops on epilepsy, the first in Chile in 2013, and the second in Honduras in 2015.

However, while countries in the Region have made progress, there remain areas that require a greater effort. Key challenges faced by the Region include the fact that while the majority of countries in Latin America and the Caribbean have the four basic epilepsy drugs in their arsenal, often they are only available at the secondary and tertiary levels of care. Furthermore, there is a high proportion of psychiatric comorbidity with epilepsy that often goes unrecognized and is therefore not treated properly. And in many countries, people with epilepsy are still denied the ability to exercise their fundamental human rights. Sometimes it is not a matter of having the legal instruments in place to guarantee these rights, but of enforcing them.

In order to address these barriers and strengthen epilepsy efforts in the Caribbean, PAHO organized a two-day workshop with country counterparts in the subregion to enhance country capacity to deliver evidence-based care to people with epilepsy within the framework of PAHO Strategy and Plan of Action on Epilepsy. This report details the content of this workshop and concludes with recommendations for follow-up.

## **Aim and Objectives**

### Aims of the workshop:

The aim of this workshop was to strengthen country capacity to deliver evidence-based care to people with epilepsy within the framework of PAHO Strategy and Plan of Action on Epilepsy. This is also broadly based on the Resolution WHA68.20, adapted by the World Health Assembly in 2015, urging countries to strengthen effective leadership and governance for general health, mental health, and noncommunicable disease (NCD) policies, including consideration of the specific needs of persons with epilepsy.

### Objectives:

1. To update participants on the PAHO Regional Strategy and Plan of Action on Epilepsy;
2. To identify challenges and opportunities to improve access to services for people with epilepsy in the Caribbean;
3. To provide countries with tools, evidence and guidance on best practices to address epilepsy at primary care level; and
4. To discuss and agree on key priorities for PAHO technical cooperation related to epilepsy in the Caribbean.

## Agenda Overview

The workshop commenced with welcoming remarks from Dr. Bernadette Theodore-Gandi, PAHO/WHO representative for Trinidad and Tobago. The feature address was then delivered by Dr. Roshan Parasram, Chief Medical Officer for the Ministry of Health of Trinidad and Tobago. Mrs. Dévora Kestel presented the regional situation on epilepsy using the mid-term review of PAHO's Epilepsy Plan of Action. Drs. Samuel Wiebe, Roberto Caraballo, Marco Tulio Medina, Tomas Mesa and Carlos Acevedo followed with a panel discussion on regional collaboration in Epilepsy.

The next two presentations highlighted the Caribbean region, first in a presentation delivered by Dr. David Corbin on the state of epilepsy in the English-speaking Caribbean, followed by a panel discussion on country experiences in integrating epilepsy services into pre-existing health programs, featuring Barbados, Grenada, Jamaica, St. Lucia and Trinidad and Tobago. Each one of the countries presented advances in the provision of services for people with epilepsy and some common challenges including scarce human resources, inconsistent supplies of medication, and limited data availability.

The afternoon included a presentation on the mhGAP-IG Epilepsy module, given by Dr. Claudina Cayetano. The mhGAP is a set of guidelines used to integrate mental health into primary care, and one of its eight modules is epilepsy. The presentation on the role of family and user's associations was given by Dr. Mary Secco. Additionally, two roundtables took place: one on the need for patient advocacy in public institutions, presented by Dr. Secco, and the second on the need for patient advocacy in research, academic institutions and hospitals, presented by Dr. Jorge Burneo. The final presentation of the day on epilepsy and driving was delivered by Dr. Amza Ali. The day concluded with a plenary discussion.

The second day began with a presentation from Dévora Kestel highlighting regional and global commitments. Mrs. Kestel was followed by Dr. Juliana Vallini, who spoke about the PAHO Strategic Fund as a tool for improving the accessibility and affordability of safe AEDs. Dr. Dave Clark then presented barriers and opportunities to advancing the Epilepsy Action Plan: the role of regional and national organizations. Participants divided into groups to discuss and formulate recommendations for countries to strengthen the management of epilepsy. The day ended with conclusions and recommendations for the way forward, led by PAHO staff, ILAE, IBE and ESC representatives.

For a detailed agenda of the workshop, please refer to Annex A on page 14.

### Day 1

Epilepsy in the Americas: The Current Situation  
*Dévora Kestel, Unit Chief, Mental Health and Substance Use, PAHO*

Epilepsy is a chronic noncommunicable disorder of the brain characterized by recurrent seizures. Roughly 5 million people in the Region of the Americas are affected by epilepsy, which accounts for 0.7% of the regional burden of disease. It is estimated that more than half of the people who suffer from epilepsy in Latin America and the Caribbean have no access to services. Furthermore, those with epilepsy can experience human rights abuses including restricted job opportunities, exclusion from educational systems, legal constraints to exercising particular rights, and inadequate living conditions.

In September 2011, PAHO's 51st Directing Council approved its Strategy and Plan of Action on Epilepsy 2012-2021. The Plan has four strategic lines of action: programs and legislation; health services for the treatment of people with epilepsy; education and sensitization of the population; and

information systems strengthening. In 2015, PAHO conducted a mid-term evaluation of the Regional Plan's indicators. In 2016, 18 countries had national epilepsy programs in place (2020 target: 25), and 10 countries had national legislation in line with international human rights standards (2020 target: 25). Furthermore, epilepsy mortality is still too high, averaging a rate of 0.84 per 100,000 population and reaching as high as 1.04 per 100,000 in Latin America and the Caribbean, where the Regional Plan establishes a target of less than 0.8 per 100,000.

#### Panel Discussion: Regional Collaboration in Epilepsy

##### Regional Collaboration in Epilepsy

*Tomas Mesa, Vice President of IBE International Executive Committee for Latin America*

In 2000, the first Latin American Epilepsy Congress was held, which led to the production of the Declaration of Santiago on Epilepsy in Latin America. The Declaration urges action in the following areas: developing national plans for epilepsy, strengthening primary healthcare in epilepsy, improving equipment in epilepsy, and improving access to drugs and surgery, among other priorities. Regional advancement in epilepsy has been fueled by the PAHO Regional Strategy and Plan of Action on Epilepsy, ILAE and IBE chapters located across the countries, national epilepsy programs in each country, and Latin American Epilepsy Day, celebrated annually on September 9th.

Key regional activities include two regional workshops on epilepsy, organized jointly by PAHO, ILAE and IBE: one in Santiago, Chile in 2013, and the second in Tegucigalpa, Honduras in 2015. A technical document, Epilepsy in Latin America, was produced based on presentations from those workshops. Other activities carried out on a regional level include supporting and evaluating country service user and caregiver associations for epilepsy. Dr. Mesa also presented E-Jaguar, a virtual platform to promote the communication network and the interaction between people and entities that deal with epilepsy in the Americas. E-Jaguar is part of the Strategy and Action Plan by the WHO/ILAE/IBE. He concluded the presentation by outlining the Chilean National Epilepsy Program and highlighting some of its advances and challenges.

##### Strategy and Plan of Action on Epilepsy in the Americas

*Carlos Acevedo Schwartzmann, Director, WHO Collaborating Centre for Education and Service Development for People with Epilepsy in Chile, Chile*

The Regional Strategy and Action Plan on Epilepsy, approved in 2011, was the result of participatory collaboration between PAHO, ILAE, and IBE, led by PAHO. In the last five years, the initiation of the Plan has advanced more than in previous years. Responsible for this change are the increased commitment of governments giving epilepsy priority in national plans of health, collaboration among national and regional organizations, and the active participation of ILAE and IBE in national epilepsy initiatives. Looking forward, what will be needed for successful implementation of the Plan is a redistribution of existing resources for epilepsy based on successful experiences, strong leadership in country, and recognizing that each country will have different strategic objectives and cultural differences impacting implementation.



## PAHO Strategy and Plan of Action on Epilepsy

Marco T. Medina, Director, WHO/PAHO Collaborating Centre for Research and community intervention in Epilepsy, Honduras

A launching and Regional Workshop of the Strategy and Plan of Action on Epilepsy was held in Tegucigalpa, Honduras in October 2011. In 2013, a Report on Epilepsy in Latin America and the Caribbean (LAC) was published, using data obtained from 25 LAC countries which responded to the assessment tool. Other key epilepsy organizations and initiatives in the Region include the Latin American Summer School of Epilepsy (LASSE); the Latin American Academy of Epilepsy (LAAE), founded in 2007; an epilepsy pilot project in Brazil; and the Latin American Congresses on Epilepsy, held every two years.

A key challenge for future work is addressing neurocysticercosis, an infection of the central nervous system caused by tapeworms, which represents the most frequent preventable cause of epilepsy in the developing world. Cysticercosis is endemic or suspected to be endemic in many countries in the Americas. Appropriate action will require the development of a standard methodology for intervention validated in endemic countries. In conclusion, Dr. Medina notes that PAHO's Strategy and Plan of Action on Epilepsy represents a major opportunity for ILAE, IBE and PAHO; these organizations need to address the Strategy in a step-by-step, local- and regional-oriented approach.

## ILAE Commission for Latin American Affairs

*Roberto Caraballo, Chair, International League Against Epilepsy (ILAE)*

The aim of the 2017-2021 ILAE Commission for Latin American Affairs is to build on the work of the previous Commission as well as to develop new activities. The main focus of these activities will be national programs, education, and research. Regarding national programs, the ILAE, IBE and PAHO will have to work with local governments to develop epilepsy programs and education. It is recommended to complete the general template for a national epilepsy program, which can be adapted to local situations in each country. Support should be offered in this area. Plans should work to develop primary-care-based epilepsy care, which is closely integrated with specialist services. Referral and counterreferral should also be developed to improve the management of patients. The use of telemedicine can be considered, with the aim of avoiding the need for families to travel. Telemedicine is a relatively inexpensive tool which can help in resource-poor settings.

In the area of education, the Commission will work with LASSE and the LAAE. A special emphasis will be placed on education for primary care physicians in the diagnosis and care of epilepsy in patients. National epilepsy awareness campaigns and community-based epilepsy education programs for the public should be established to reduce stigma. The Commission will also work to provide young neurologists and neurosurgeons with special training programs and fellowships. Educational tools, such as online courses and degree programs, should be developed. Interesting areas of research being investigated are the medical use of cannabis and the role of genetics.

## Remarks from Samuel Wiebe, President, International League Against Epilepsy (ILAE)

Dr. Wiebe expressed his full commitment to support the work that is being done in the Caribbean, and the importance for the ESC to have a single chapter. He acknowledged the work that PAHO has been doing in assisting to bridge efforts among the different organizations with the understanding that a crucial element for success is people on the ground. Dr. Wiebe also noted that epilepsy is competing

with many other diseases and the importance of engaging local people as advocates.

State of Epilepsy Care in the English-Speaking Caribbean  
David Corbin, President, Epilepsy Society of the Caribbean

Dr. Corbin presented a definition of epilepsy and age-specific incidence by gender and etiology. He cited a 2016 article from *Practical Neurology* to highlight the limits of epilepsy care in this particular subregion; the article shares the observations of a 2015 epilepsy educational tour to Guyana funded in part by the ILAE and the Epilepsy Foundation of Guyana. The tour found no practicing neurologist, no electroencephalogram (EEG), and a limited range of AEDs in most places. Current data show a scarcity of neurospecialists (neurologists and neurosurgeons) in English-speaking Caribbean countries in general as well as a lack of neurodiagnostic facilities (having access to EEG, computed tomography (CT) and magnetic resonance imaging (MRI) scanners), the majority of which are privately operated. Dr. Corbin used Antigua, St. Lucia and Tobago as examples of smaller Caribbean islands implementing initiatives to improve epilepsy management. Additional barriers to treating patients with epilepsy in Anglophone Caribbean highlighted by Dr. Corbin included a lack of specialists and/or diagnostic equipment, financial barriers on an individual or country level, long waiting times for consultation and tests, long distances to travel to access routine care within or outside home territories, reduced employment opportunities due to epilepsy, and the lack of sustained availability of newer and safer AEDs.

Panel Discussion: Country Experiences on Integrating Epilepsy into Pre-Existing Health Programs

Epilepsy in Barbados  
*Simeona Jacinto, Queen Elizabeth Hospital, Barbados*

Barbados has an epilepsy mortality rate of 2.4 per 100,000, which represents a decrease of 23.7% since 1990. More than half (52%) of all hospital admissions for epilepsy are in adults, most commonly in the age range of 31-40 years. In children, the most common age range for admission is 1-10 years. Publicly funded facilities for treating epilepsy include Queen Elizabeth Hospital (which houses a neurology outpatient clinic, an inpatient service, a neurophysiology lab, and radiological and laboratory services), and polyclinics. Private resources include a privately-owned hospital and medical centers, CT and MRI equipment, EEG, and professionals (neurologists, internists, pediatricians, and family physicians).

Among the challenges for epilepsy care in Barbados are the heavy economic burden of long-term pharmacotherapy and frequent hospitalizations; medical comorbidities including mental illness; pharmacoresistance; medication non-compliance; and managing certain lifestyle factors. Dr. Jacinto recommended four areas for improving epilepsy care: expanding specialist services (EEG monitoring, epilepsy surgery programs, diet therapy, and electrical stimulation therapy); patient-centered care; public education; and physician education.

How Epilepsy Services Can Be Integrated into Pre-existing Health Programs in Jamaica  
Amza Ali, Senior consultant in medicine and neurology, Kingston Public Hospital

Epilepsy services and quality of care vary greatly in the country, both geographically and by type of facility (public versus private). Despite the recent training of an epilepsy surgeon who will return this year, Jamaica suffers from a shortage of essential epilepsy team members, particularly neurologists. Neurologists, internists and pediatricians provide most epilepsy services. The Epilepsy Society of the Caribbean and the Jamaican Epilepsy Association (JEA) provide education, both to medical professionals and the population. MRI and EEG services are available. However, there exist numerous challenges, including keeping collaborators and colleagues motivated, a slow legal system, stigma, and the lack of a surgical program.

Lessons learned for the country center on the need to continue to build local, regional and international collaborations; finding innovative ways for bringing private capital into specialized healthcare; not losing sight of non-surgical initiatives; and nurturing the evolution of smaller advocacy groups on each island. Going forward, Dr. Ali emphasized the necessity of building broad consensus, working across sectors, research, mentorship, and persistence.

Epilepsy in the Tri-Island State of Grenada  
Justin La Rose, Ministry of Health, Grenada

In Grenada, the lack of data on epilepsy presents a challenge to quantifying affected subgroups. However, it is known that the greatest incidence of new onset occurs mostly in the population under 18 years old. New onset in adults is often secondary to cerebral anatomic lesions, and alcohol abuse also accounts for new onset in the adult population (metabolic/toxic disorder). Epilepsy services are provided on three levels of care: primary (in health centers and private clinics and offices); secondary (in health facilities such as rural hospitals); and tertiary (in the General Hospital).

Cultural challenges to epilepsy care in the country include the fact that the disorder is still considered a societal taboo. Some patients do not seek medical attention for seizures and others are non-compliant with their treatment. Other challenges are the inconsistent availability of some drugs and devices (e.g. EEG) and working with patients so that they actively participate in the management of their epilepsy. Dr. La Rose pointed out the need for an established protocol in the country to better streamline epilepsy management.

Epilepsy Care in St. Lucia  
*C. Nathaniel, Victoria Hospital, St. Lucia*

St. Lucia counts on 33 public clinics, 1 polyclinic, and 2 small hospitals. Its two main hospitals, Victoria and Saint Jude's, have public clinics. While there is no neurologist in country, there is currently a neurosurgeon and a visiting neurologist from Martinique who sees patients at the private hospital, Taipon. Most adults with seizures are seen by internists, district medical officers, general practitioners and emergency room physicians, while children are seen by pediatricians. Since 2012, epilepsy clinics have been run twice a year, which offer EEGs. However, they receive no funding from the Ministry of Health. CT scans are only available at Taipon Hospital. Many people will travel to Martinique for an MRI.

Lessons learned about epilepsy care in the country included the following: overseas collaboration with specialists has been helpful, especially in the case of lectures they have given on correctly diagnosing and treating people with epilepsy; and the increasing availability and affordability of AEDs has improved the control of epilepsy. Yet, challenges persist, including the lack of specialty care and imaging services, limited financial resources, and the continued education of patients and their families.

Epilepsy Care in Trinidad and Tobago: Moving from Chronic Diseases to Specialized Care  
*Avidesh Panday, St. Augustine Private Hospital, Trinidad and Tobago*

Trinidad and Tobago currently have access to 8 neurologists, 8 neurosurgeons, and a neuropsychologist. There is only one pediatric neurologist. Medical social work departments and neurophysiology technicians provide key support services. Challenges to epilepsy care in the country include recruiting pediatric neurologists, developing partnerships between established Neurophysiology Training Schools and COSTAAT, reforming epilepsy care at the tertiary level, and integrating epilepsy into social and

occupational areas (e.g. driving, working, etc.). Dr. Panday shared the following lessons learned: the referral policy must be amended and streamlined; there needs to be a more streamlined way for the integration of private referrals into the public system; there exists a clear discrepancy between adult and pediatric epilepsy services; more support staff (EEG technicians, psychologists, etc.) are needed; and lastly, that trust between epilepsy patients and doctors needs to be addressed. He concluded by suggesting that rather than move patients to the hospital, personnel should go to the patients in secondary care. Following that, tertiary care services should be built up.

#### Introduction to mhGAP Epilepsy Module

*Claudina Cayetano, Regional Advisor on Mental Health, PAHO*

The Mental Health Gap Action Programme Intervention Guide (mhGAP-IG) is a WHO program, launched in 2008, to scale up care for mental, neurological and substance use disorders (MNS). Its focus is to increase the capacity of non-specialized health care providers to address the unmet needs of people with priority MNS conditions. mhGAP-IG training teaches core competencies relevant to assessing, managing and providing follow-up for people with MNS conditions. The training is interactive and incorporates role plays, case studies and quizzes. Supervision support starts after training and is ongoing.

mhGAP-IG Version 2.0 consists of eight modules, including one on epilepsy. The module provides a quick overview of the disorder as well as an algorithm for assessing, managing and providing follow-up for epilepsy cases. The recommended duration of the training for this module is 4.5 hours. Additionally, when doing the training, it is important to introduce the module on Essential Care and Practice (ECP), which outlines the principles of essential care for all people seeking health care and aims to promote respect for the privacy of people seeking care and foster good relationships between health care providers, service users and their careers. The recommended training for the ECP module is 5.8 hours.

#### The Role of Family and User's Associations: Advantages and Impact on the Community: Successful Anti-stigma Initiatives

*Mary Secco, Secretary General – International Bureau for Epilepsy*

The presentation defined user and family member associations as well as different types of stigma (felt vs. enacted stigma). Stigma can result in discrimination which poses barriers to accessing education, employment and key rights such as marrying or obtaining a driver's license. Dr. Secco presented the results of a study in which Epilepsy Southwestern Ontario piloted an epilepsy education program for 5<sup>th</sup> grade students in Canada. Classes that received the program showed significant increases in epilepsy knowledge and attitudes about epilepsy, further supporting the need for epilepsy interventions to recognize the important role of epilepsy-related stigma on disease burden and quality of life.

Education and sensitization of people with epilepsy and their families is a key component of empowerment and treatment. Clinic to Community (C2C) provides 60-minute education sessions to people with epilepsy and their family members using three steps to coordinate care. The program helped parents of children with epilepsy feel less anxious and more confident in their ability to prevent injuries.

#### The Need for Patient Advocacy in Public Institutions: Schools and Work

*Mary Secco, Secretary General – International Bureau for Epilepsy*

A lack of school support for children with epilepsy can impede their academic, behavioral, and social

development, leading to unsatisfactory adult lives marked by incomplete education, unemployment, poverty, social isolation, inadvertent pregnancy, and psychiatric disorders. School support has been identified as a top priority by many parents of children with epilepsy.

Epilepsy Southwestern Ontario provides a variety of services to help teachers and school staff accommodate children with epilepsy and seizure disorders. These include brief training presentations on topics such as seizure first aid medication and learning strategies for students with epilepsy, as well as help with the development of individualized seizure response protocols.

The Need for Patient Advocacy: Research, Academic Institutions and Hospitals  
Jorge Burneo, President, Canadian League Against Epilepsy (CLAE)

Dr. Burneo described the current relationship between Western University Hospital and The Epilepsy Support Centre, a patient advocacy group in Ontario, Canada, which provides education and support services to people affected by epilepsy; the Hospital refers patients to this support center so that they can learn more about community resources and meet other people with epilepsy. The Epilepsy Support Centre also provides first seizure aid and advocacy for patients by helping them navigate legal and social resources. The Hospital hosts educational sessions organized by the Support Centre and helps the organization with fundraising and support of its operation.

Advocacy groups also play an important role in epilepsy research; they suggest issues for concern among those affected by epilepsy, advocate for government funding for research and participate in research projects. These groups can continue to provide advocacy through hospitals, deliver crucial educational services in clinics, emergency rooms and in the community, and advocate for research in university and government settings.

Epilepsy and Driving: The Caribbean Case  
*Amza Ali, Senior consultant in medicine and neurology, Kingston Public Hospital*

Driving by persons with epilepsy (PWE) has been the subject of intense debate since the early 20th century, resulting in a general ban on driving by PWE. In 1956, the UK was the first country to establish a seizure-free period (of 5 years). In the English-speaking Caribbean, driving by PWE has not been permitted since 1938. Non-independent Caribbean islands have enacted brief restriction periods on driving (typically between 1 and 2 years) following a seizure. The Acts that prohibit PWE from driving in many English-speaking Caribbean countries lag behind international trends in granting drivers licenses to persons with disabilities and can be inconsistent (providing exception to persons making a temporary stay in the country). In practice, PWE and doctors often struggle to navigate the regulations, with doctors usually passing the decision on to neurologists, whose advice to patients can vary greatly.

Data support the modification of these restrictive laws; only 11% of all car crashes involving PWE were due to seizures (Hansotia and Broste), and there exists a low proportionate mortality ratio of 0.2 in PWE. Furthermore, the relative risk of car accidents is comparable to that of people with other noncommunicable diseases. However, gaining support for changes in the law can be challenging due to tension between appeasing the general population and the regulatory authorities and creating restrictions with which patients would actually comply. A 2011 study conducted by Dr. Ali also showed public perceptions of PWE driving to be an additional barrier to removing the current regulations.

## Day 2

### Regional and Global Commitments

*Dévora Kestel, Unit Chief, Mental Health and Substance Use, PAHO*

There is a commitment on a global level to develop a report on the epilepsy situation. Similarly, PAHO's Action Plan requests a new report on the regional situation to be developed by 2020. The last regional report was published in 2013, and it has been challenging to collect epilepsy data; validity is often lacking or highly variable, which can result from the involvement of different organizations.

The global data collection exercise is being developed by ILAE/IBE in coordination with the WHO. There is a need to ensure coordination and collaboration between these organizations and local health authorities, to obtain good quality data in the region.

### Improving the Accessibility and Affordability of Safe AEDs: An Overview of the PAHO Strategic Fund

*Juliana V. Borges Vallini, Specialist at the PAHO Strategic Fund, PAHO*

The lack of access to safe, efficacious and quality medicines and other health technologies is a persistent problem in the Region. The Pan American Health Organization has three mandates that promote the accessibility and affordability of safe AEDs: The Regional Strategy on Universal Access to Health and UHC, Accesses and Rational Use of Strategic and High-cost Medicines and Other Health Technologies, and the Regional Epilepsy Strategy.

The PAHO Strategic Fund is a mechanism for the pooled procurement of essential medicines and strategic health supplies. Since its creation in 2000, the Fund has procured 150 products for more than 30 countries and territories at a value of more than US \$90 million. The Strategic Fund for Medicines provides a timely and continuous supply of safe and affordable products, including anti-epileptics. Its Revolving Fund provides benefits to both countries and drug manufacturers. The Fund can assist in improving epilepsy management and care by strengthening comprehensive actions to guarantee universal access and response to epilepsy and by optimizing national, subregional, regional efforts and strategies.

### Barriers and Opportunities to Advance with the Commitments to Implement the PAHO Epilepsy Action Plan: The Role of Regional and National Organizations

*Dave Clarke, Baylor College of Medicine, Texas, United States*

This presentation highlighted the importance of having a point person or advocate in the community as well as the need to assess comorbidities and work with social sectors. Also important are more comprehensive assessments of functional limitations and child and family impact. Disparities across the Caribbean in terms of access to care can make regional collaboration difficult. However, addressing Island-specific needs (e.g. research, surgery and clinical care through education and advocacy) will help get health professionals and the population involved.

Dr. Clarke suggested the following long-term goals: facilitating the improvement of health care services directly by providing governmental education and advocacy and education to the families of people with epilepsy; training staff at all levels; teleconferencing on difficult patients on a regional or international level; establishing stronger regional neuropsychology–social worker partnerships for epilepsy; and establishing regional epilepsy surgery. In the shorter term, actions could include developing online

educational materials with easy access and making available assessment tools that have been objectively tested.

Future partnerships could focus on strategic collaboration with PAHO and the Latin American Commission, neurology trainees, education and training modules, and Neurotech Ltd, with continuous North American Commission affiliation and input. The presentation concluded with the following recommendations for the way forward: determine the need; work together in a coordinated fashion; maximize involvement; audit everything; seek help when necessary; and keep it exciting.

### Group Work

Participants were divided into two groups and given a series of questions on country-level priority actions for epilepsy. They were also asked to provide concrete recommendations for operationalization of the four strategic lines of action of the Regional Strategy and Plan of Action on Epilepsy in the Caribbean. The aim of the working group session was to ensure that delegates left with actionable steps for implementation of epilepsy programs in their respective countries. Working groups were followed by a plenary session where each group had the opportunity to present on their discussion and recommendations.

*For Line of Action 1* (Programs and legislation for the care of people with epilepsy and protection of their human rights), recommendations for operationalization included developing consensus among Caribbean islands on the need for program development and supporting legislation, especially those related to rights and driving.

*For Line of Action 2* (Health Services network for the treatment of people with epilepsy, with emphasis on primary health care and provision of drugs), recommendations centered around the use of telemedicine, access to medication by using the PAHO Strategic Fund, the need to continue collaboration with regional partners, as well as training in mhGAP in the module on epilepsy. Given the limited resources, another recommendation was the training of specialty nurses.

*For Line of Action 3* (Education and sensitization of the population, including people with epilepsy and their families), key recommendations included taking advantage of Epilepsy Day/Week or Purple Day, and advocacy and outreach activities in schools and in the community.

*For Line of Action 4* (Strengthen of the ability to produce, assess, and use information on epilepsy), participants recommended a database for epilepsy patients or available services for epilepsy, and support for research on prevalence, treatment and knowledge gaps.



## Follow-up and Recommendations

- There was a strong agreement by participants to use the PAHO Strategic Fund for consistent accessibility to AEDs. The process of accessing the fund will be supported in collaboration with Juliana Vallini, who will also provide information about regulatory perspective in the Caribbean countries.
- Encourage ESC members to attend the Latin American Congress on Epilepsy, which will take place in San Jose Costa Rica from 29 September to 2 October 2018. This will be a good opportunity for ESC members to strengthen collaboration with colleagues from Latin America. Additionally, if ESC member receive support to participate at the Congress in Costa Rica, they will be in a better position to provide an update on activities in the Caribbean.
- Monthly WebEx sessions will be scheduled for the next 6 months, convened and coordinated by PAHO's Mental Health Unit. Having this regular follow-up will assist members of ESC to support activities in the subregion.
- Follow up with the Mental Health Focal Points in PAHO country offices regarding local activities that participating countries agreed to implement.
- Participants agreed upon a list of discussion topics for future collaboration.

## Annexes

### Annex A: Workshop Agenda

## AGENDA

# Improving the management of epilepsy and its comorbidities in the Caribbean

**Day 1, 28 February 2018**

**Moderator: Taraleen Malcom**

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|                       |   |
|-----------------------|---|
| 8:15 – 8:30 a.m.      | <b>Participants Registration</b>  |
| 8:30 – 8:50 a.m.      | <b>Welcome Greetings from PAHO/WHO/TTO</b><br>Dr. Bernadette Theodore-Gandi<br>PAHO/WHO Representative, Trinidad and Tobago   |
|                       | <b>Feature address</b><br>Chief Medical Officer, Dr. Roshan Parasram<br>Minister of Health  |
| 8:50 – 9:30 a.m.      | <b>Regional situation on Epilepsy</b><br>Midterm Review of PAHO Epilepsy Plan of Action<br>Dévora Kestel  |
| 9:30 – 10:30 a.m.     | <b>Regional Collaboration in Epilepsy</b><br>Partnership collaboration with PAHO for epilepsy awareness<br><br>Panel discussion: Representative of ILAE and IBE<br>Samuel Wiebe, Roberto Carballo, Marco Tulio Medina, Tomas Mesa,<br>and Carlos Acevedo. |
| 10:30 – 10:45 a.m.    | <b>Question and Answers</b>   |
| 10:45 – 11:00 a.m.    | <b>Coffee Break</b>   |
| 11:00 – 11:30 a.m.    | <b>State of Epilepsy Care in the English-Speaking Caribbean</b><br>David Corbin   |
| 11:30 a.m.-12:30 p.m. | <b>How epilepsy services can become integrated into pre-existing</b>  |

**health programs**

Panel discussions on country experiences:

Barbados, Grenada, Jamaica, St. Lucia and Trinidad and Tobago

12:30-2:00 p.m.

**LUNCH**

2:00-2:30 p.m.

**mhGAP, Module of Epilepsy**

Claudina Cayetano

2:30-3:10 p.m.

**The role of family and user's associations; advantages and impact on the community**

Discussing the effect that stigma has on job hunting, security and successful anti-stigma initiatives

Mary Secco

3:10-3:30 p.m.

**Coffee Break**

3:30-4:10 p.m.

Round Table

**The need for Patient Advocacy in Public Institution: Schools and Work**

Mary Secco

**The need for patient advocacy:** research, academic institutions and hospitals

Jorge Burneo

4:10-4:50 p.m.

**Epilepsy and Driving**

Amza Ali

4:50-5:15 p.m.

**Plenary discussion**

5:30 p.m.

**Adjournment**

**Day 2, 1 March 2018**  
**Moderator: Claudina Cayetano**

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|                       |   |
|-----------------------|---|
| 8:15-8:40 a.m.        | <b>Summary of Day 1</b>   |
| 8:40-9:00 a.m.        | <b>Regional and Global Commitments</b><br>Dévora Kestel   |
| 9:00-9:30 a.m.        | <b>Improving the accessibility and affordability of safe AEDs</b><br>Juliana Vallini  |
| 9:30-10:00 a.m.       | <b>Question and Answers</b>   |
| 10:00-10:30 a.m.      | <b>Coffee Break</b>   |
| 10:30-10:45 a.m.      | <b>Barriers and Opportunities to advance with the commitments to implement the Epilepsy Action Plan; The role of regional and national organizations</b><br>Dave Clarke   |
| 10:45 a.m.-12:30 p.m. | <b>Group work:</b><br>The aim of the group work is to discuss and formulate recommendations for countries as they identify country level requirements to strengthen the management of epilepsy<br><br><b>Plenary</b>                            |
| 1:30-1:30 p.m.        | <b>Conclusions and Recommendations on the way forward</b><br><br>PAHO staff<br><br>Regional Partners:<br>International League against Epilepsy (ILAE)<br>International Bureau against Epilepsy (IBE)<br>Epilepsy Society of the Caribbean (ESC) |
| 1:30-2:30 p.m.        | <b>LUNCH</b>  |
| 2:30-3:00 p.m.        | <b>Adjournment</b>  |

## Annex B: Participant List

| Caribbean Meeting on Epilepsy TTO Workshop 28 Feb-1 Mar 2018 |            |                  |                  |  |
|--|------------|------------------|------------------|--|
|  | First name | Last name        |                  | Email  |
| 1  | Carlos     | Acevedo          | Chile            | <a href="mailto:carloredoacevedo@yahoo.com">carloredoacevedo@yahoo.com</a> |
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