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From the International Bureau for Epilepsy

Strategy and Plan of Action for Epilepsy 2018

1. Origin and development

In August 2010, during the International Bureau for Epilepsy (IBE)/International League Against Epilepsy (ILAE) Latin American Epilepsy Congress, a meeting was held between the Pan American Health Organization (PAHO), the IBE, and the ILAE. At this meeting, Dr. Jorge Rodríguez participated as Head of Unit, Mental Health and Substance Abuse of the PAHO/WHO; Mike Glynn as IBE President; Solomon Moshe as ILAE President; Carlos Acevedo and Tomás Mesa as representatives of the IBE Latin American Regional Committee; Dr. Marco Tulio Medina representing the ILAE Commission on Latin American Affairs.

At that meeting, it was agreed to create a Plan of Action and Strategy for Epilepsy considering that more than 50% of people with epilepsy (PWE) living in Latin America and the Caribbean lack access to services, and also, that the stigma, due to lack of education and knowledge that surrounds PWE, is an obstacle to the exercise of their human rights and social integration. Given the advances in the knowledge and management of epilepsy, together with political will, it was considered a crucial moment for PAHO and its member states to prioritize this important public health problem.

Thus, a *Task Force* was created to create a document to be presented to the PAHO Board of Directors. A consultation process was held with the ILAE, the IBE, Ministries of Health, the WHO Department of Mental Health and Substance Abuse, civil societies at the national level, PAHO technical bodies, as well as a group of experts and other interested parties. Resulting from this consultation, several drafts were prepared, which were circulated to IBE and ILAE chapters in the Latin American and Caribbean regions, and later edited by Dr. Jorge Rodríguez for presentation to the 51st Directing Council of the Pan American Regional Committee, 20th to 30th of September 2011, when it was approved unanimously by its members.

Its development has allowed the incorporation of epilepsy as a health priority for the decade 2011–2021. The launch of the Strategic Plan took place in November 2011 in Honduras, when a *Memorandum of Understanding* was also signed between the authorities of WHO–ILAE–IBE. In January 2012, the presidents of IBE and ILAE sent a letter to each of the Ministers of Health of member countries of the region. This, in turn, served as a letter of introduction for the presidents of the national IBE and ILAE chapters, allowing them better access to the ministries of health and helping to establish contact with the local PAHO delegates in each country.

2. Strategic areas and comparative balance

The strategic areas of the Strategic Plan are the following:

1. Programs and legislation for PWE and the protection of their human rights,
2. Network of health services for the care of PWE, with emphasis on primary healthcare and the provision of AEDs,
3. Education and awareness raising of the general public, including PWE and their families, and
4. Strengthening the capacity to produce, evaluate, and use information about epilepsy.

The following indicators are presented in a comparative way: baseline, goal, and current status of each strategic area:

Strategic areas and comparative balance

Strategic area 1: Programs and legislation for people with epilepsy care and protection of their human rights.		
Objective	Indicator, baseline, and goal	State
1.1	**1.1.1** Number of countries that have a national care program of epilepsy underway. Baseline: 10 countries in 2010. Goal: 20 in 2015; 30 in 2020.	18 countries in 2016 *(14, 15)*. The goals were too ambitious. The goal is to adjust it to 25 countries for 2020.
1.2	**1.2.1** Number of countries that have checked/modified and updated the legislative framework related to epilepsy, according to the international	10 countries in 2016 *(14, 15)*. There is no unanimous agreement among countries about the need for a specific law for epilepsy. The suggestion is to reduce the

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(*continued*)

Strategic area 1: Programs and legislation for people with epilepsy care and protection of their human rights.		
Objective	Indicator, baseline, and goal	State
	standard of human rights. Baseline: no defined in the 2012. Goal: 10 countries in 2015; 25 in 2020.	goal to 15 countries for 2020.
	1.2.2 The instrument and methodology for full assessment of national programs and care services for epilepsy are developed and published (IEPE). Baseline: any instrument published in 2010. Goal: 1 instrument published in 2012; 1 checked in 2020.	Execution of a survey on basic data of programs, services, and resources in 2013 *(14)*. Revision of the questionnaire in light of the WHO Neurology Atlas, in progress.
	1.2.3 Number of countries that have assessed its national program and/or care services for epilepsy. Baseline: any country in 2010. Goal: 25 countries in 2014; 30 in 2020.	There is no specific information. The suggestion is to align this indicator with 1.1 and reconsider the goal to 20 countries for 2020.
	1.2.4 Regional mortality rate for epilepsy (for 100,000 inhabitants). Baseline: 0.8 in 2010. Goal: <0.8 (the plan does not indicate the year).	Rate for 100,000 inhabitants in 2012 (the most recent available information): North America: 0.50 Latin America: 1.04 The Caribbean: 0.84
Strategic area 2: Health services net for people with epilepsy care, highlighting primary care and drug supply.		
Objective	Indicator, baseline, and goal	State
2.1	**2.1.1** A regional training unit (guide) on epilepsy, based on skills required to satisfy needs and addressed to primary healthcare workers, has been developed and published. Baseline: 1 guide for 2010 (mhGAP-IG). Goal: 1 guide developed to regional level in 2013; 1 guide checked in 2020.	The procedural guide for epilepsy of the mhGAP program, published by WHO in 2010, accomplishes the requirements of the regional training unit suggested by this indicator. This guide, including the epilepsy unit, has been published and is available for the countries of the region in English (2010), French (2011), Spanish (2012), and Portuguese (2015). Also, this unit has been created to the country level, and it is being used in about 30 countries and territories, according to WHO's methodology *(12)*.
2.2	**2.2.1** Percentage of people with epilepsy that do not receive treatment. Baseline: 60% in 2009 Goal: 30% in 2020	Pilot study in Honduras with a procedure program in a community. Treatment gap reduction from 53% in 1997 to 13% in 2014 *(14)*. A new regional study is expected for 2017 to analyze the treatment gap, similar to the one performed in 2013 on the treatment gap in mental health. All countries of the region that have available data will be included.
Strategic area 3: Education and raising awareness in the population, including people with epilepsy and their families.		
Objective	Indicator, baseline, and goal	Status
3.2	**3.2.1** Drafting and publication of regional guides for the creation and implementation of epilepsy prevention actions in each country. Baseline: any guide in 2010. Goal: 1 guide in 2013; checked in 2020.	The document related to regional guides for the creation and implementation of epilepsy prevention actions was carried out in 2016. It is expected to be finished by the first semester of 2017.
Strategic area 4: Strengthening the ability to produce, assess, and use information about epilepsy.		
Objective	Indicator, baseline, and goal	Status
4.1	**4.1.1** Publication of a regional and methodological document for the development of epilepsy indicators, carried out through an enquiry process and the participation of a group of experts. Baseline: any document in 2010. Goal: 1 document in 2014.	This has been partially accomplished, with the indicators-data use of the *PAHO Regional Report* and the *WHO ATLAS for Neurological Disorders (14,15)*. It must be achieved in the period 2017–2020.
	4.1.2 Regional report on epilepsy, finished and published. Baseline: 1 report in 2008. Goal: 1 in 2015; 1 in 2020.	Report on *Epilepsy in Latin America, 2013 (14)*.
4.2	**4.2.1** Publication of a compilation of epidemiological research on epilepsy in the Latin American and Caribbean regions. Baseline: any publication in 2010. Goal: 1 in 2015; 1 in 2020.	A technical document that gathers the most important experiences in Latin America in the field of epilepsy (programs, services, and epidemiological research) has been published based on two regional workshops that were carried out in Chile (2013) and in Honduras (2015) *(14)*.

3. Strategy and Action Plan, midterm report

In June 2017, a midterm report on progress made in each area was presented. The balance is positive and important progress has been made. However, barriers persist:

⇒ At the country level, not all have committed themselves optimally.
⇒ Coordination between authorities and professional associations has not been as expected, and even access to health authorities has sometimes been complicated and imperfect.

4. How to overcome the problems that have been generated?

1. Adjust the goals of the Strategy and Action Plan for Epilepsy so that they reflect more realistic goals.
2. Not all countries have the same problems. It is necessary to establish local priorities according to each country, evaluating the existing needs and resources, to make a rational use of them.
3. Search for the economic resources that development of these activities requires.
4. We must acknowledge that there are cultural differences in the region, and there is significant inequality among countries, including large differences between different geographical areas of the same country (Honduras).
5. Improve communications through social networking platforms, both between the IBE and the ILAE chapters, Collaborating Centers (CC), national governments, PAHO, and groups of PWE and/or relatives; strengthen the social network E-Jaguar that exists for this purpose, to make communications more effective.

5. Practical efforts

1. As an example of practical effort, during the last two Latin American Epilepsy Congresses (Mexico 2016 and Costa Rica 2018), and using those countries that already have epilepsy legislation in place as examples (Colombia and Argentina), workshops on epilepsy and the law were organized, resulting to the creation of a Working Committee with PAHO, to establish a common denominator on the rights and obligations of PWE.

2. On the other hand, two epilepsy CC have been created, one in the Chilean League against Epilepsy — "WHO Collaborating Center for Education and Service Development for People with Epilepsy" (2014–2018 and reaccreditation 2018–2022), and a second CC in Honduras — "WHO Collaborating Center for Research and Community Intervention in Epilepsy" (2016).

6. Challenges: we have 3 years left, what should we do?

1. We must work collectively as a team involving PAHO–WHO–IBE–ILAE Ministries of Health, politicians in decision-making in the area of health.
2. Strengthen primary healthcare and incorporate the mhGAP educational and training module for epilepsy.
3. Improve availability and access to cheap, safe, and quality AEDs.
4. Provide comprehensive epilepsy treatment, considering the social, educational, and legislative aspects that defend the human rights of the PWE.
5. Integrate epilepsy with other chronic disease health programs, aimed at the prevention of epilepsy: cerebrovascular accident, brain injury, and professional attention for pregnant women and childbirth.
6. Vaccines for infections of the central nervous system.
7. Strengthen educational interventions at the level of patients and their families, in the school environment, the workplace, and in the community in general.
8. Hold a workshop in the Central American and Caribbean regions in the first semester of 2019 to analyze these challenges and also, to initiate a process leading to the request of an extension by PAHO for the Strategy and Plan of Action on Epilepsy for the Americas and the Caribbean.
9. Organize virtual communication networks, both between the IBE and ILAE chapters, CC, national governments, and PAHO. On the other hand, provide support to groups of PWE and their families through social networks.

7. Conclusion

Bearing in mind that the Strategy and Plan of Action for Epilepsy in Latin American and Caribbean region is a unique initiative developed jointly by WHO–ILAE–IBE and the Ministries of Health of each country, it has facilitated teamwork that has been progressively improving the regional landscape of PWE and their environment. We must continue to progress on that path and incorporate new virtual information sharing avenues that facilitate effective communication.

PHOTO CAPTION: Meeting on the Strategy and Plan of Action for Epilepsy, Barcelona, September 2017.

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