Epilepsy Week in Latin America

The 9th of September is a special day for the whole community and for all of us who work in the field of Epilepsy in Latin America. On September 9, 2000, 19 years ago at the opening of the 1st Latin-American Congress of Epilepsy in Santiago, Chile in the framework of the Global Campaign Against Epilepsy – endorsed by the International League Against Epilepsy (ILAE), the International Bureau for Epilepsy (IBE), and the World Health Organization (WHO) – this date was established as the Latin-American Epilepsy Day.

From that day onwards, the efforts of the countries adhering to this campaign and organizations dedicated to improving the quality of life of people with this chronic condition in Latin America, have worked together to improve the comprehensive management of epilepsy and to increase the awareness of disease and the problems of patients and their families, not only on the 9th of September, but always.

For all of us in Latin America, this date represents a moment of reflection to evaluate the achievements and the challenges that are pending to ensure that people with epilepsy can fully function in our society; that is, how much progress we have made in our commitment to carry forward the vision and mission of the ILAE.

In different countries of the region each year during the week before or after the 9th of September, conferences and/or other activities are held aimed at the continuous training of neurologists, clinicians, neurophysiology technicians, nurses, teachers, and the community at large to identify people with epilepsy, offer them antiepileptic drugs, and provide information to avoid stigma, discrimination and negative attitudes that are more harmful to the person with epilepsy than the disease itself.

Nevertheless, the Epilepsy Weeks that took place in Bolivia, Paraguay and El Salvador were organized with the idea of promoting national programs in countries where academic and social activities are less numerous, national congresses are not held, and resources are scarce. In these countries, with the support of ILAE LA, IBE LA, PAHO and the different local chapters, these activities were carried out with a high impact on the medical community, technicians in neurophysiology, nurses, patients and their families, and the general public. It is important to communicate these achievements to the different stakeholders in the region, national chapters, ILAE-LA, ILAE executive committee, and others who work to improve the comprehensive care for people with epilepsy.

The week is not always organized coinciding with Epilepsy Day, but on dates that favor the attendance of professionals representing ILAE-LA, IBE-LA, and PAHO, as well as other professionals in the region.
Epilepsy Week in Bolivia

The project of the Epilepsy Week was started 5 years ago in Bolivia and then carried out in different cities and regions of the country in subsequent years. The first week of epilepsy in Bolivia took place in the city of Santa Cruz in 2015, the second in La Paz in 2016, the third in Sucre in 2017, the fourth in Tarija in 2018, and the fifth in Cochabamba from 15 to 20 June 2019.

This latest edition of epilepsy week in Bolivia in Cochabamba was organized according to the different lines of the project: Education of patients and families, reduction of discrimination and stigma in the society, training of primary health-care workers, support from the authorities, and research.

In the framework of education and awareness of the population, including people with epilepsy and their families, there were training courses with educational material in two different cities of the country.

To reduce the stigma, discrimination, and social exclusion of people with epilepsy, a country-wide advertising campaign was held including a press conference, media tours, distribution of educational material and the video 'What does it mean to live epilepsy.'

For health-care workers in primary care and medical students, a course was held to improve skills in the diagnosis and management of epilepsy at three different locations in the country.

In a meeting with the authorities the need for the creation of epilepsy centers and the control of quality and prices of antiepileptic drugs was emphasized. These projects will be supported by PAHO.

Finally, a symposium was held for epilepsy specialists (neurologists, child neurologists, educational therapists, psychiatrists, and EEG technicians with case discussions and update lectures.
Epilepsy week in Paraguay

The Epilepsy Week in Paraguay was held from April 8 to 13, 2019. During the week there were scientific, social and cultural activities to increase awareness of Epilepsy at the level of Public Health in different locations in the country.

A scientific international meeting was held for neurologists, neurosurgeons, neuropediatricians, clinicians, general pediatricians, primary care physicians, medical students, nurses. During the meeting three different courses were given: Update in Epilepsy (ALADE), Primary Care in Epilepsy, and Electroencephalography. Additionally, relationships were established with the best epilepsy centers in Latin America.

Different training courses were held for patients, family members, and the general public at the most important hospitals in the country. The week closed with an artistic show with the presence of authorities who committed to participate actively in the implementation of a national epilepsy program.

There was active participation of the general public. Furthermore, the ALADE course had 59 attendees (specialists), the EEG course 35 (doctors and technicians), and the course of Primary Care in Epilepsy 118 (family doctors, young physicians, and medical students).

A media agency was in charge of the dissemination of Epilepsy Week with information for television, radio, the press, and the social media.
The first Epilepsy Week in El Salvador took place from September 1 to 7, 2019 with a large series of academic and cultural events.

Activities began on September 1 with the first 5-km marathon for epilepsy, a unique event that attracted more than 150 participants, including doctors, paramedics, patients, and family members, both professional and amateur runners with the goal of raising awareness of epilepsy in the general public.

On September 2 and 3, visits were made to universities and hospitals to give update lectures on epilepsy and its management and discussion of clinical cases with participation of medical students and residents of internal medicine and neurology. Attendance was over 200 in some of the lectures.

More than 30 specialists participated in the symposium for neurologists discussing the situation of epilepsy in Latin America and the classification of epilepsy, among other topics.

On September 6, a press conference was held for the media to publicize the national and regional problems related to epilepsy and strategies to address these problems. Simultaneously, at the Tin Marín Children’s Museum, playful activities were presented that allowed epilepsy specialists to talk to children about the disease and what to do when someone has a seizure. The play "Carlitos and Epilepsy" was presented with a message of non-stigmatization of the disease to more than 300 children in just one morning.

The courses of Epilepsy in Primary Care and Electroencephalography for technicians took place on September 4 and 5, and were attended by physicians and family medicine, internal medicine, and neurology residents, and EEG technicians, respectively, from across the country.
The week concluded with the International Symposium on Epilepsy which took place on September 6 and 7 including activities for medical and paramedical personnel, and patients and their families while a simultaneous EEG Meeting was held for technicians.

In conclusion

The Epilepsy Week is an excellent opportunity to raise awareness of the disease in the general population and regional authorities. Currently, in the region the Epilepsy Week is used to promote programs in resource-poor countries.

The success of the week is largely due to a comprehensive program methodology that provides information to the general public, training for workers in the field of primary health care and a scientific meeting for neurology specialists and technicians.

Dissemination of the week in the media contributes to increasing the impact of activities.

Yearly repetition of the event and the organization of Epilepsy Weeks in other Latin American countries will be a challenge for the future.