



# United Through Epilepsy

First workshop for young people with epilepsy in Latino America and the Caribbean

29th September - 2nd October 2018  
San José, Costa Rica

## WORKSHOP REPORT

# United Through Epilepsy:

Report from the First encounter for Young People with Epilepsy  
in Latino America and the Caribbean

Authors: Mesa, JT<sup>1</sup>; Lara, S<sup>2</sup>, Núñez, L<sup>3</sup>; Mesa, T<sup>4</sup>, Monterrey, P<sup>5</sup>; Brodie, M<sup>6</sup>.

1. Pediatric neurologist, Hospital Clínico de Magallanes, Punta Arenas, Chile
2. Clinical Psychologist, Hospital San Juan de Dios, San José, Costa Rica
3. Neurologist at Centro Medico Nacional “20 de Noviembre”, Ciudad de México, México. President of the Mexican Neurology and Psychiatry Society.
4. Pediatric neurologist, Pontificia Universidad Católica de Chile, Santiago, Chile. Vicepresident for Latinoamérica IBE International. Executive Committee
5. Neurologist, Hospital de Alajuela, Alajuela, Costa Rica
6. Clinical and research director of the Epilepsy Unit at Western Infirmary, Glasgow University, Glasgow, Scotland. President of the International Bureau of Epilepsy.

## Introduction:

During the last two decades, Latin-America has been witness to huge development in the epilepsy field. Starting with the “Out of the shadows” global initiative lunched by the World Health Organization (WHO), the International League Against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE), and soon followed by the first regional congress held in Santiago, Chile in 2000, many improvements in science, research, clinical issues, politics and patient care have been achieved. As experience grows, the involvement of areas, other than academic and investigation, has become relevant for the treatment and caregiving of People With Epilepsy (PWE).

Between 2008 and 2011, the Pan American Health Organization (PAHO), the ILAE and the IBE worked together in order to publish initial reports on epilepsy in Latino American and Caribbean countries (LAC)<sup>1</sup>. Important conclusions show that two-thirds of these countries do not have a health sector program for epilepsy care and 80 percent of the LAC countries do not have appropriate legislation related to epilepsy. As a consequence, the human and civil rights of PWE are frequently violated.

This has made epilepsy a public health priority and has identified strategic plans for the next decade 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.

After approval of the Resolution on Epilepsy by the World Health Assembly (WHA) in May 2015, eight main issues were established to urge member states to undertake activities to reduce the global burden of epilepsy<sup>2</sup>. The WHA resolution highlights the need to engage civil society on these matters. This has meant important steps forward putting epilepsy on the global health care agenda. Awareness that clinical improvements must run side by side with economic, political and legislative changes has motivated the need to involve authorities in these fields to become part of congress sessions and discussion: With all of them taking part in decision-taking, the patients point of view and interventions are of upmost importance for societal change in our common mission. Similar efforts undertaken in other regions show that increasing awareness of epilepsy at every level of society is necessary to reduce the social burden and stigma associated with epilepsy<sup>3</sup>.

The EpilepsyNext initiative, developed by the IBE under the direction of its President, Dr. Martin Brodie, has focused on young people with epilepsy through a range of project modules. One of these involves youth



summits, a gathering of young people with epilepsy from different countries to share their personal experience, to debate the issues relating to epilepsy and to propose solutions for problems on stigmatization and burden. This model, first applied on 2014 in Washington, USA by the IBE North America Regional Committee, gathered 20 young adults from 4 different countries: Canada, Jamaica, Puerto Rico and USA. The summit generated multimedia material that has been useful for diffusion emphasizing histories of success and self-progress.

### Activity description:

Following public and health strategies, in order to reduce the global burden on epilepsy, a first workshop for young people with epilepsy was organised during the 10th Latino American Epilepsy Congress in San Jose, Costa Rica (29th September to 2nd October 2018). The main objective was to give the opportunity to young people with epilepsy to share experiences with their peers from other Latin American countries and to learn more about their illness. Furthermore, through the provision of education on epilepsy, to encourage them to be leaders in their national epilepsy associations.

For the selection of the candidates, ILAE and IBE invited Latin American and Caribbean chapters to submit applications. For the first event, 11 participants arrived from five different countries: Brazil, Chile, Costa Rica, Mexico and El Salvador. Support and guidance of the participants was provided during the entire schedule by two coordinators (a psychologist and a physician) on topics including basic information about epilepsy, diagnosis and current treatments.

On the first day of activities the participants attended the IBE Day sessions that included talks about epilepsy treatment, comorbidities, living with epilepsy, stigma, sports, and other topics, having the opportunity to interact actively with questions to the speakers and a sharing of personal experiences.

The second day was dedicated to two workshops on epilepsy and media, and epilepsy and law, developed by IBE committee members, government authorities, and the World Health Organization (WHO) delegate, in an attempt to create local and regional strategies for a better quality of life for PWE.

Finally, third day was reserved for friendship and social interaction between participants during activities that included:

- Tour in San Jose City and surroundings,
- Gastronomic and cultural presentation of each country,

- Making a short video of the group with a message for other PWE.

### Discussion:

Having the opportunity to share time with young PWE was a unique experience to develop solidarity and friendship. After three days of work, there was general agreement that the activity was useful and important.

On the day of arrival the candidates were amazed to meet other young people with the same medical condition. One commented that he did not know other young PWE until then. They felt free to be themselves, because they knew they were not going to be judged or overprotected. They sat down to talk and realized that they had many things in common.

Talks during the IBE Day sessions were meaningful for all participants and encouraged them to report own experiences. This was beneficial for both the person that loses fear and gains trust in themselves, and for other PWE to realize that she/he is not alone with her/his illness. One of the young PWE said that IBE Day helped her to accept her epilepsy diagnosis. She had



been struggling with her diagnosis and the change this had brought to her lifestyle. Furthermore, meeting young people with her same illness made her feel that she was not alone and helped her to understand that having epilepsy is a big opportunity to do something great with her life.

During the cultural exchange evening, the young people had the opportunity to learn about other cultures, to realize that they were not alone, that there are people around the world with whom they have many similarities. They did not imagine that having epilepsy might not be all negative but that, on the contrary, it opens doors. They realized that they are not different from other young people, that they can do the same as them, live a full life. That they can change how other people treat them.

We sincerely feel that sharing experiences, analyzing problems in other regions where cultures are different has made all of them realize the need for major interventions in society. The main problems detected by them were issues related to stigmatization on social relationships, family overprotection, educational and employment limitations, discrimination and public misinformation.

The participants managed to propose multiple strategies for taking account of these problems (see table), some of which are currently under active development by them. Comments from the participants make us

## Strategies to address the problems faced by people with epilepsy

- Create an accessible epilepsy video repository
- Use media opportunities for awareness raising and education of the public
- Address the employment market
- Build relationships with companies for employment benefits
- Own story testimony
- Develop social media pages for epilepsy education
- Organise national and regional meetings for people with epilepsy
- Lobby for improvements in public health provision and legislation amendments

feel that this encounter was such a big opportunity for them to look for hope and to encourage each one to create opportunities that may be helpful for other PWE in their homeland, transforming epilepsy from a burden to an opportunity.

Limitations for the first workshop were related to selection process. All Latin American countries were invited to send participants, but the lack of local chapters in many countries, in particular in Central American and Caribbean countries, as well as not having enough funds to cover candidates' expenses, reduced the participant numbers. Other minor problems, such as chronic illness of participants, travel jetlag and antiepileptic drug timing problems, and seizure risks during the stay were present but did not constitute a major issue.

In conclusion, the young PWE learned to see their illness from a positive side, a side full of opportunities. The final message of this workshop was "Thanks to epilepsy we were able meet", "Epilepsy is part of us, but it does not make us different from others". We look forward to repeating this experience during next LACE, hoping that all countries in the region will be represented.

Special acknowledgment to Alma Paez for her work in putting arrangements in place. Without her and the support of IBE, nothing could have happened.

## References:

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>*
2. World Health Organization. *Executive Board, 136th Session. Global Burden of Epilepsy and the Need for Coordinated Action at the Country Level to Address its Health, Social and Public Knowledge Implications, Geneva, 2015 Available at: <http://www.ilae.org/Visitors/News/documents/WHO-Epilepsy-2015.pdf>. Accessed November 10, 2017.*
3. Baulac, M; de Boer, H; Elger, C; Glynn, M; Kalviainen, R; Little, A; Mifsud, J; Perucca, E; Pitkanen, A; Ryvlin, P. *Epilepsy priorities in Europe: A report of the ILAE-IBE Epilepsy Advocacy Europe Task Force. Epilepsia, 56(11):1687-1695, 2015 doi: 10.1111/epi.13201*