

2018 Annual Report - ILAE-North America

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The commission's goals are aligned with those of the ILAE, namely to: (1) serve all health professionals as a premier international resource for current and emerging knowledge on epilepsy prevention, diagnosis, treatment, and research; (2) serve as an international information resource and leader for optimal, comprehensive epilepsy care.

Our goals are to (1) continue to contribute to the development of our future epilepsy leaders; (2) contribute to the advancement of knowledge by creating a regional congress; (3) contribute to trainee education by supporting activities such as the Epilepsy San Servolo Summer Course and Leadership Development; (4) continue to address ongoing issues related to approval of antiepileptic drugs with regulators, including the EMA, PMDA, and possibly FDA. These issues include extrapolation of results in adults and children, use of AEDs in monotherapy, shortening placebo exposure through time to event designs; and (5) work with PAHO and relevant stakeholders to advance epilepsy care and education, and implement aspects of the PAHO epilepsy strategic plan in ILAE-NA countries.

Leadership Development Course

The Leadership Development Course, designed to train the next generation of ILAE leaders in essential skills, has been successfully held at the past two IEC meetings. The course is taught by leaders in epilepsy across the world; sessions include strategic planning, budget preparation, negotiations, and personal leadership style. In order to serve specific needs of regional commissions, a course was held in August 2018 at the ILAE Europe meeting in Vienna, Austria. The course was very well received. Another course is planned for 2019 IEC in Bangkok, Thailand. The course is designed and executed in collaboration with the global leadership development taskforce of ILAE, and regional commission chairs.

Recommendations for Future Work

Another Leadership Development course is planned for 2019 IEC in Bangkok.

Global Health Task Force

This was the first year of the Global Health Task Force, which was created with the intent of expanding the scope of Intercommission Educational Outreach. The mission of the task force is to advance epilepsy education and care internationally. The task force has representation from the three chapters in ILAE-NA, as well as representation from the ILAE/IBE Global Outreach Task Force.

In 2018, the task force worked on two reports. The first was the construction of a repository that identifies ongoing global health projects in epilepsy (educational and clinical) that emanate from countries within ILAE-NA. The concept is to identify individuals, countries, and needs to foster communication, collaboration, and the pooling of resources to maximize ILAE global impact. The repository was largely created through two surveys; one based in the United States and one based in Canada. The second report consisted of a review of the literature over the last few years on global health in epilepsy.

Recommendations for Future Work

The plan is to make the repository of global health in epilepsy available as an online resource through the ILAE website. The first step will be to pilot the success of this online resource with the ILAE-NA projects, after which it will be open to all regions. The repository should allow for collection of data on the design of successful projects and identify specific needs in underserved regions, with the main goal of improving the impact of future projects. The task force would also like to begin to create global health priorities in epilepsy education and care.

Task Force on Regulatory Affairs

The goal of the Task Force on Regulatory Affairs is to monitor key ongoing issues related to approval of antiepileptic drugs with regulators, including EMA, PMDA, and FDA.

Recent ongoing activities have significantly focused on the following issues:

- 1) Due to efforts by the regulatory task force and others, approval for antiepileptic drugs (AEDs) in adults with focal epilepsy can now be extrapolated down to the age of four in the US and Europe, provided that studies are done to support safety and pharmacokinetics. However, studies to demonstrate efficacy are still required for infants down to the age of one month. These studies currently require two inpatient stays in video-EEG monitoring units, making them impractical. The task force has joined forces with the ILAE Pediatric Commission to develop a new trial design specifically for this age group.
- 2) We continue to work with colleagues in the ILAE (specifically the Task Force on Women and Pregnancy) to discuss our concerns about EMA restrictions on the use of valproate in women.
- 3) We are in the process of providing ILAE feedback to EMA regarding their newly released draft guidance.

Recommendations for Future Work

We will continue to work on the new infant epilepsy protocol, with the intent of publishing it. We will be present at the Research Roundtable for Epilepsy taking place March 22-23, 2019 to discuss this and other regulatory issues with both the FDA and EMA. We will address other regulatory issues as they arise. We intend to have a 1:1 meeting with EMA and possibly PMDA in 2020, in Geneva, Switzerland.

PAHO Taskforce

The PAHO taskforce emerged out of the meeting held in Trinidad in March 2018 hosted by PAHO, and to which executive members of the ILAE, members of its Commission on North American Affairs, members of the Latin American Commission and members of the Epilepsy Society of the Caribbean (ESC) were invited. Presentations by Caribbean physicians from several islands led to the identification of shared problems across the region. Having members working in North America in attendance at this meeting highlighted the intention of North America to assist in improving epilepsy care in the comparatively underserved Caribbean. Importantly, having recognised the opportunity for strategic alignment with PAHO's goals and that the longstanding presence of PAHO in the Caribbean region would be helpful in expediting future joint initiatives, the PAHO ILAE Taskforce was formed.

Specific goals for sub-committees established included the following:

- Changing **driving regulations** in the region which presently preclude driving by anyone with epilepsy, regardless of control.
- Formation of local individual **island chapters** of the International Bureau for Epilepsy (IBE) to address social needs of PWE.
- Training of **specialist epilepsy nurses**, initially in Jamaica, to help provide better access to advise and to care of PWE in these islands.
- Identifying **anti-epileptic drugs needed in each island**, and to facilitate their availability, utilising, if necessary, PAHO's strategic funds.

These sub-committees are chaired by ESC members with particular interest in these issues. Since then, Dr Morris Scantlebury has drafted a document for a wider range of anti-seizure drugs for Barbados, which has been submitted to Dr Claudina Cayetano of PAHO. It will be a template for other islands to produce similar documents for individual islands, as needs differ across the region.

Following this Trinidad meeting, another important development was the approval by the ILAE-NA of a Demonstration Project to address restrictive driving regulations in the Caribbean, beginning with Antigua. It will start by identifying relevant stakeholders, and then to form a team to develop appropriate regulations that can be moved through the legislative process for implementation within the next 2-3 years. Once done, these regulations will be championed throughout the Caribbean Community (CARICOM) for wider regional implementation.

Nathalie Jetté
Chair, ILAE-North America

Recommendations for Future Work [Sharon, see note above]

The PAHO Taskforce will continue to work, through its subcommittees, on widening its efforts to include smaller islands which presently are not adequately included in the activities of the Epilepsy Society of the Caribbean. Reinforcing and building relationships with PAHO will be an ongoing strategic objective of this ILAE Taskforce.

Education Task Force

The Education Task Force was tasked in 2018 to begin preparing for the ILAE-NA regional conferences. The task force works in close liaison with the AES, ESC and CLAE to coordinate efforts in planning for those associations' scientific meetings and the regional conferences. The rotations will be in the following order: Canada, US, Caribbean. The next round of regional meetings will be as follows: 1) 2020 – congress in Canada and a smaller session at AES; 2) 2022 – larger session at AES (half or full day; to be determined); and 3) 2024 – congress in Caribbean and a smaller session at AES.

San Servolo Epilepsy Course

The ILAE-NA provided funding for an attendee from a low resource country to attend the San Servolo course. In the future, we will target candidates from the Caribbean region in order to support our efforts to increase knowledge and improve epilepsy care in that region.

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