

# ILAE-North America



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Eileen Murray (USA), Executive Director, AES  
Amza Ali (Jamaica), Past President, Epilepsy Society of the Caribbean  
Paolo Federico (Canada), President, CLAE  
Taylor Abel (USA), YES  
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### Management Committee Liaison

Samuel Wiebe (Canada), MC Liaison

## Aims and Goals of the Commission

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 were to (1) contribute to the development of our future epilepsy leaders; (2) contribute to the advancement of knowledge by organizing a regional congress; (3) contribute to the education of trainees and early career clinicians and scientists by supporting activities such as courses in clinical epilepsy, the neuropsychology of epilepsy, basic science mechanisms, and Leadership Development; (4) 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; (6) improve knowledge and health care expertise in underserved areas of the NA region, specifically the Caribbean; (7) establish a repository of global health initiatives to advance epilepsy education and care internationally.

## **Commission Activities and Accomplishments**

### **North American Virtual Epilepsy Meeting**

The North American Virtual Epilepsy Meeting, the first ILAE regional meeting in the North American region, took place 25-27 September 2020. The meeting was adapted from a face-to-face meeting to a virtual meeting as a response to COVID-19 restrictions and was the first of the ILAE Congresses to take place virtually. The final registration number exceeded 500.

The programme comprised lectures and interactive sessions on a broad range of topics highly relevant to recent scientific, clinical and social developments in epilepsy. The NAEC was an accredited meeting, approved as an Accredited Group Learning Activity by the Royal College of Physicians and Surgeons of Canada. Sessions were made available on demand for a period of 12 weeks after the meeting, which encouraged registrations.

Feedback for the meeting was very positive with 94% of respondents saying the meeting met or exceeded their expectations while 88% of respondents agreed that the programme met the stated learning objectives

### **Centre-to-Centre Program (Canada-Trinidad)**

The Centre-to-Centre program (chaired by Dr. Dang Nguyen) aims to improve the care of patients with epilepsy in the Caribbean Islands by pairing a mentee centre from one Caribbean country to a mentor centre from Canada. In a pilot trial, the Eric Williams Medical Complex (Trinidad) was paired with the Montreal University Health Centre. The first year of the program (2019) was quite successful, ending with a 3-day course in Trinidad in November 2019. Dr. Nicholas Maraj, an adult neurologist, one of the identified local leaders who had already come to Montreal in 2019, was able to come for a second training visit in January 2020. COVID-19 impacted significantly on the Centre-to-Centre program, with cancellation of training visits to Montreal and of a planned 3-day course in Trinidad. Training of local leaders (Dr. Maraj and Dr. Vanita Shukla, a pediatric neurologist) continued in a virtual fashion with monthly webinars, EEG training sessions with embedded quizzes, and bursaries to attend the Virtual North American Region Epilepsy Congress.

### **Leadership Development Course**

The Leadership Development Task Force (Drs. Jaideep Kapur and Sheryl Haut) has been conducting training programs since 2015, and over 100 individuals have been trained in these programs. Due to the COVID-19 pandemic, the regional ILAE Leadership Development Program which was scheduled to take place at the 1st ILAE North American Regional Congress in September 2020 was deferred.

### **Global Health Task Force 2020**

This was the third year of the Global Health Task Force (GHTF; chaired by Dr. Karen Parko) which was created with the intent of expanding the scope of the Intercommission on Educational Outreach. The mission of the task force is to advance epilepsy education and care internationally. The task force has 16 members with representation from the three chapters in ILAE-NA as well as representation from the ILAE Global Advocacy Council.

In 2020 the task force held three virtual meetings. The goals for the year were to finish the launch of the repository within ILAE-NA and create a plan for outreach to include all ILAE regions.

The online repository (constructed in the preceding years) was successfully launched at the 2019 American Epilepsy Society meeting. It is housed within the ILAE-NA web area (<https://www.ilae.org/regions-and-countries/regions/ilae-north-america/global-health-database>). The goal and mission of the repository is to improve the care of persons with epilepsy globally by increasing collaboration, reducing redundancy, directing resources, promoting advocacy, and identifying volunteers, as well as targeting potential funding for future global health projects.

In 2020 the GHTF worked with the new ILAE Global Advocacy Council (GAC) to reposition the repository into the GAC website where it would become an international resource.

The GHTF also organized the Global Health Special Interest Group session during the American Epilepsy Society annual meeting in 2020, and has done so annually since the task force's inception in 2018. This year, they were able to bring together epileptologists from Kenya, South Africa, Mexico, and the USA via the meeting's virtual platform, in line with the mission of collaboration and education within the global epilepsy community.

### **Pan American Health Organization (PAHO) Task Force**

The PAHO-ILAE Task Force (chaired by Drs. Amza Ali and Dave Clarke) emerged out of a meeting held in Trinidad in March 2018 hosted by PAHO and to which Executive members of the ILAE, members of its Committee for the North American Region, members of the Latin American Commission and members of the Epilepsy Society of the Caribbean (ESC) were invited.

Several goals were identified for this collaboration, including increasing the availability of anti-seizure medications and improving driving regulations in the Caribbean. With regards to the first priority, Dr. Morris Scantlebury drafted a document that calls for a wider range of anti-seizure medicines for Barbados, which has been submitted to Dr. Claudina Cayetano of PAHO. This template will then be used to produce similar documents for the other individual islands as needs differ across the region. The new initiative of the ESC to harmonize protocols for managing status epilepticus across the English-speaking Caribbean fits well with the mandate of this Taskforce.

The most pressing issue of widest Caribbean relevance is that of inadequate driving regulations. In recognition of this a Demonstration Project was launched by ILAE North America to address restrictive driving regulations in the Caribbean, beginning with Antigua. Relevant stakeholders were identified. During the latter part of 2019, the concept emerged of hosting a symposium on Driving in the Caribbean to be held in June 2020. Unfortunately, the advent of the COVID-19 pandemic and its significant impact on these small islands, both directly from infectious sequelae but also indirectly by its economic impact, has made it difficult to advance this initiative during this year and the planned June meeting was postponed, possibly to October 2021.

### **Recommendations for Future Work**

In 2021, the Canada-Trinidad Centre-to-Centre Program plans to: a) offer pre-recorded webinars on epilepsy to Trinidad medical students and internal medicine residents rotating in neurology; b) continue with virtual EEG training courses; c) establish virtual clinics every two months; and d) hopefully a 3-day in-person epilepsy course in Trinidad in November 2021.

The Leadership Development Task Force is planning to hold the next ILAE Leadership Development Program at the upcoming International Epilepsy Congress in Paris in August 2021. The curriculum is being adapted based on previous participant evaluations, and expanded topics in response to the current times (i.e., conducting effective zoom meetings). Similar to prior years, the course will take place over one and a half days, however it will be conducted either in person, virtual or a hybrid based on the decisions of the ILAE Executive Committee. If the course is held in person, it will include networking opportunities with ILAE Executives and other invited faculty and leaders as feasible.

In 2021, the Global Health Task Force plans to devise a dissemination plan for other ILAE regions to access interest and participation in the repository. The overall goal is to implement a sustainable international global health directory that will serve as the “go-to” place for anyone around the world working in global health and epilepsy.

The PAHO Task Force hopes to be able to travel in 2021 and meet in person, as much of what we hope to achieve will be through networking to establish personal relationships that will need to be honed and matured.

The Education Task Force will organize a North American Region Symposium to be held at the 2021 American Epilepsy Society Conference.

Members of the ILAE-NA committee will be assisting the ILAE with translation of materials into French for the Pediatric Epilepsy Training Course.

Submitted by Dr. Nathalie Jetté and Dr. Mary Lou Smith