

NORTH AMERICAN COMMISSION



Sheryl Haut

Commission Members:

Chair	Sheryl Haut (USA)
Past Chair	Jacqueline French (USA)
EC Liaison	Samuel Wiebe (Canada)
Treasurer	Lionel Carmant (Canada)
Secretary	Sharon Whiting (Canada)
Education Officer	Jaideep Kapur (USA) Amza Ali (Jamaica)
Liaison to Global Outreach Information Officer	William Theodore (USA) Nathalie Jetté (Canada)

Subcommissions and Members Task Force on Access to Care:

Stigma Task Force: Natalie Jetté (Chair) and 14 international members

Education Task Force: Jaideep Kapur (Chair, USA), Sheryl Haut (USA), Jose Cavazos (USA), Nizam Ahmad (Canada), Lionel Carmant (Africa program)

Task Force on Regulatory Harmonization: Members: Jacqueline French (Chair, USA), Meir Bialer (Israel), Steven Schachter (USA) (tri-chairs), Michel Baulac (France), Emilia Bagiella (statistician), Alexi Arzimanoglou (France), Eugen Trinkka (Austria), Scott Mintzer (USA), Emilio Perucca (Italy)

Task Force for Caribbean Development: Amza Ali (Chair, Jamaica), Sharon Whiting (Canada, formerly Jamaica), David Clarke (U.S. formerly from Antigua), Lionel Carmant (Canada)

Hispaniola Task Force: Lionel Carmant (Chair, Canada), Marco Medina (Latin American Commission), Diogenes Santos-Viloria (Dominican Republic), Michel Baldy Mouliner (EUREPA), Alex Elie (Haiti), Marcel Sévere (Haiti), Farah Lubin (USA), Jose Ferreira (USA).

PAHO Task Force: Sheryl Haut (Chair, NAC), William Theodore (AES-IAC), Nathalie Jetté (Canada), Jaideep Kapur (USA), Jorge Burneo (Canada)

Institute of Medicine: Sheryl Haut (Chair, NAC); NAC members

Aims

The Commission established seven task forces to accomplish the stated goals.

Commission Activities from July 2012 through July 2013

Goal 1: ILAE shall serve all health professions as the premier international resource for current and emerging knowledge on epilepsy prevention, diagnosis, treatment, and research.

- Systematic review of stigma in epilepsy literature — results to be disseminated in *Epilepsia* and Montreal

Systematic review: The Stigma Task Force has nearly completed reviewing 700 full text articles identified by review of 4,123 abstracts related to stigma in epilepsy. Data abstraction began in April 2013 with results anticipated and manuscript preparation planned by spring/summer 2013.

Stigma Symposium: ILAE meeting, Montreal 2013. The symposium proposal submitted jointly by NAC and the Commission on Stigma was accepted for the upcoming Montreal meeting, chaired by Dr. Jetté. Main Session: Stigma in epilepsy: who, why and what to do?

- Translation project - pilot Spanish translation of two symposia at AES, expansion to be explored

Translation was provided for two symposia at AES 2012. The translation units were utilized by a very small number of attendees. The need and future of this program will be discussed with the Latin American Commission in Montreal.

- Visiting professorships – good project for export to other regions

Strengths: Has established enduring collaborations between centers; has effected local change

Challenges: Identifying needs and assessing outcomes; identifying appropriate sites; choosing partnerships with long-term potential

The PECA program has continued to support partnerships between epilepsy centers in the Americas to promote education and improvements in epilepsy care. Over 25 visits have been completed through this program, with more in process. In the current year, the focus has been on funding reverse visits by Latin American faculty to visit North American Centers. The NAC has been working closely with the LAC on a joint project of funding these visits.

This program was more recently extended to Africa, in collaboration with the African Commission. The education task force worked with Dr. Carmant and the African Commission to develop a call for proposals for visiting professorships to Africa, and supported these fellowships. The task force and others reviewed the proposals and selected the top three for funding. These visits took place and three more are planned for 2013.

- Telemedicine

The telemedicine project now exists between Yale and Jamaica, towards the development of an epilepsy surgery program in the Caribbean.

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- International symposia/courses

The NAC has established a joint-symposium plan with the EUC. The NAC-AES symposium is shared with the EUC every other year; similarly the EUC symposium at the European Congress is shared with AES every other year. In addition, the NAC has sponsored symposia at the International Epilepsy Congress, and the Regional Caribbean Congresses.

- Regulatory affairs

The task force on regulatory harmonization in collaboration with the European Commission has had a series of meetings with members of the FDA and the EMA. The goal of this effort is to identify and refine the optimal clinical trial methodologies for new anti-epileptic drugs. A seminal meeting took place in Paris in 2011 with a follow up meeting at the Eilat conference in May 2012, focused on three areas: 1. New study design for monotherapy trials, which the FDA is willing to consider; 2. Approval for pediatric age groups when adult trials have been performed for the same indication, which the EMA has accepted and the FDA will consider; 3. Novel "time to event" trial design, which both the EMA and FDA are willing to consider pending new data analysis pooled from multiple studies.

A white paper is in process to propose the elimination of separate indications for monotherapy and add-on therapy. Similarly, a white paper is being considered to present the pediatric approval proposal to the FDA following a meeting (the PEACE meeting) in collaboration with the FDA this fall. It is anticipated that these manuscripts positioned as white papers dealing with these regulatory issues will be submitted by the end of this NAC term. The meeting planned with the FDA for 2013 will help to direct these efforts.

- Neuro-cysticercosis prevalence project – manuscript in late 2012

Phase 2 of the neurocysticercosis project involves testing 125 control subjects with no history of seizures, to match the epilepsy prevalence identified in Phase 1. This work continues but has been slowed due to internal elections.

Goal 2: ILAE shall serve as an international information resource and leader for optimal, comprehensive epilepsy care.

- IOM report – dissemination of recommendations

The NAC, with the ILAE, participated in the release of the IOM report on epilepsy, and has continued to work with IOM Healthcare providers group on the implementation of the IOM recommendations. Most recently, the NAC provided an inventory of activities related to specific IOM recommendations. NAC

members have also been active participants in the epilepsy screening tool initiative, one of the first deliverables of the IOM.

- PAHO initiative – implementation will be a major focus for the NAC during the remaining 18 months of the term.

The PAHO task force of the NAC has been working closely with the PAHO task force of the Latin American Commission, as well as other members representing the ILAE including Drs. Mathern, Beghi and Hesdorffer. Following an initial meeting in 2011, a large meeting took place at the Latin American Congress in November 2012, where the NAC worked in concert with the Latin American Commission, the European Commission, the Epidemiology Commission and the Global Outreach Commissions to help formulate a roadmap for the implementation of PAHO over the coming years. The NAC representatives provided insights into many projects consistent with the PAHO mandate that have been successfully completed during the past two terms. Additionally, the IOM report provided potential examples of regulatory progress in epilepsy care and this will be discussed. As the PAHO epilepsy initiative is in its early stages, it is anticipated that the NAC will continue to be closely involved in PAHO in the coming term, including participation in the PAHO meeting scheduled in Santiago 2013.

- Formation of the Epilepsy Society of the Caribbean

The Caribbean task force, in collaboration with the ILAE executive committee, has been extremely successful in forming a new ILAE chapter, namely the Epilepsy Society of the Caribbean. This chapter received provisional approval by the ILAE, pending ratification by the general assembly in 2013. The announcement of this approval was made at the Caribbean Regional Epilepsy Congress in Antigua 2012, a successful meeting which was attended by health care professionals from 11 Caribbean islands. The NAC supported travel awards for junior Caribbean faculty to attend this congress.

Goal 3: ILAE shall work to ensure its ongoing organizational and financial viability

- Travel support

The NAC has supported travel by Drs. Ali and Clarke to build and develop a clinical epilepsy service in Antigua, an island which previously had no specific epilepsy care. The NAC has also supported travel by Caribbean physicians to the Caribbean Regional Epilepsy Congresses.

- Website development

The NAC website has been updated, but further improvement is planned for the next term.

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Challenge

- Incorporating the work of topic-oriented commissions

The NAC is joining with the Classification Commission and a new ILAE working group towards development of a conversion document for ICD-10.

- Disparities study needs to be done

To be discussed with the new Commission.

Charge

- Understand the role of the Commission in the implementation of PAHO initiative.

Commission Members 2013-2017

Sheryl Haut, Chair (USA)

Jose Cavazos (Canada)

Jaideep Kapur (USA)

Nathalie Jetté (Canada)

Dave Clarke (USA)

Vincente Iragui-Madoz (USA)

Solomon Moshé, EC Liaison (USA)