

NORTH AMERICAN COMMISSION

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	William Theodore (USA)
Information Officer	Nathalie Jetté (Canada)

Subcommissions and Members Task force on Access to Care:

Stigma Task Force: Natalie Jette (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 Trinka (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 Jette (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.

1. The Education Task Force continues to focus on the Partnering in the Americas (PECA) program, as indicated below. The Task Force has also been working to fully develop visiting professorships to Africa, and has sponsored Spanish translation of a number of symposia at AES.
2. The Regulatory Guidelines Task Force met with EMA and FDA with future meetings planned. Specific activities are described below.

3. The Hispaniola Task Force has focused on the rebuilding and maintenance of the epilepsy clinic in Haiti, the neurocysticercosis project in the Dominican Republic (DR), and the epilepsy surgery program in DR. Expansion of the epilepsy clinic and neurocysticercosis projects are described below. The epilepsy surgery program in DR has continued to be successful.
4. The Caribbean Task Forces efforts culminated in the formation of the Epilepsy Society of the Caribbean, an ILAE Caribbean Chapter which received provisional acceptance in 2012. Additionally, the Task Force planned the 3rd regional meeting of the Epilepsy Society of the Caribbean, and continued many activities towards the development of epilepsy surgery in Jamaica. Specific activities are described below.
5. The Stigma Task Force convened a large group of reviewers with representatives from the following ILAE Commissions: African, Asian Oceania, Latin American, European and North American. These experts are examining thousands of abstracts related to stigma, details below.
6. The newly formed PAHO Task Force has worked closely with the Latin American Commission and PAHO representatives towards shared goals.
7. The IOM Task Force participated in the release of the IOM report and has been active in ongoing Vision 20-20 activities.
8. North America Regional Congresses: The NAC has continued to sponsor an annual symposium at AES.

The current North American Regional Commission (NAC) was constituted in 2006, comprising English-speaking North American Chapters of Canada, the United States of America, and the English-speaking Caribbean (represented by Jamaica). The Mexican Chapter, although geographically in North America, is a member of the Latin American Regional Commission. The Commission's overall goal is to improve the delivery of epilepsy care throughout the Americas and the Caribbean.

Commission Activities from July 2011 through July 2012

Stigma Task Force: 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.

Education Task Force

PECA Program: The PECA program has continued to support partnerships between epilepsy centers in the Americas to promote education and improvements in

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epilepsy care. Over 20 visits have been completed through this program, with more in process.

Translation program: The NAC supported a pilot translation project at the AES Annual Meeting in 2011, funding a Spanish translation of the NAC symposium. We expanded the program at the AES Annual Meeting in 2012 with sponsorship of Spanish translation for the Annual Course, and two additional symposia including the NAC symposium on epilepsy classification.

Visiting Professorships to Africa: 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.

Task Force on Regulatory Harmonization: The Task Force worked in collaboration with the European Commission on 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 antiepileptic drugs.

Caribbean Task Force: This Task Force has focused on the development of the Epilepsy Society of the Caribbean, an ILAE Chapter, described more fully below. In addition, the Task Force helped organize the Caribbean Regional Epilepsy Congress in Antigua 2012, a successful meeting which was attended by healthcare professionals from 11 Caribbean islands. The NAC supported travel awards for junior Caribbean faculty to attend this Congress.

- **Epilepsy surgery program in Jamaica:** The Task Force has supported a telemedicine project between Yale and Jamaica, toward the development of an epilepsy surgery program in the Caribbean. The next steps include reverse training visits for a neurosurgeon and neuropsychologist from Jamaica to Yale
- **Epilepsy program in Antigua:** 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

Hispaniola Task Force:

- **Haiti: Visiting professorships and telemedicine:** The Task Force has performed bi-monthly visits in the region of Saint-Marc and Cange since March 2012 (Dr Carmant twice, Dr Elysee, Dr Bigelow and Dr Pierre-Louis once each). Dr Etienne will finish the six-visit program in February 2013
- **Haiti: Neonatal seizure program:** The new neonatal seizure program has included 45 neonatal EEGs interpreted by Dr Carmant
- **Dominican Republic: Neurocysticercosis project:** 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

- **Dominican Republic: Epilepsy surgery:** The Hispaniola Task Force as well as visits funded by the PECA program have been instrumental in the development of epilepsy surgery in DR. To date, more than 12 lesionectomies have been performed.

PAHO Task Force: 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 last year, a large meeting is planned for the Latin American Congress in November 2012, where the NAC will work 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.

IOM Task Force: The NAC, with the ILAE, participated in the release of the IOM report on epilepsy, and has continued to work with the 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.

Accomplishments (2011-2012)

Stigma Task Force:

- Data abstraction to begin Jan 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 Jette. Main Session: 'Stigma in epilepsy – who, why and what to do?'

Education Task Force: 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.

- **Translation program:** The NAC supported translation at the AES Annual Meeting in 2012 with sponsorship of Spanish translation for the Annual Course, and two additional symposia including the NAC symposium on epilepsy classification
- **Visiting Professorships to Africa:** Two of three funded African professorships have taken place very successfully during 2012, with the third scheduled for 2013. A call for proposals is underway for 2013 programs

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- **Task Force on Regulatory Harmonization:** 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.

Caribbean Task Force:

- The 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 healthcare professionals from 11 Caribbean islands. The NAC supported travel awards for junior Caribbean faculty to attend this Congress
- **Epilepsy surgery program in Jamaica:** The Task Force has supported a telemedicine project between Yale and Jamaica, toward the development of an epilepsy surgery program in the Caribbean. The next steps include reverse training visits for a neurosurgeon and neuropsychologist from Jamaica to Yale
- **Epilepsy program in Antigua:** 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.

Hispaniola Task Force:

- During each professorship visit to Haiti, the visiting faculty teaches medical students and family physician residents, as well as one local physician who sees patients with the team and who will complete formal EEG/Epilepsy training at CLIDEP after the January visit. It is anticipated that Partners in Health will equip each center with an EEG machine that will be linked to CLIDEP for telemedicine purposes
- **Neonatal seizure project:** Due to the high prevalence of neonatal asphyxia, a neonatal cooling program is being discussed, but maternal care needs to be improved as well
- **Dominican Republic epilepsy surgery:** To date, more than 12 lesionectomies have been performed.

PAHO Task Force:

- Following an initial meeting last year, a large meeting took place in Quito, Ecuador with the Latin American Congress in November 2012. The NAC continues to work 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 provide insights into many projects consistent with the PAHO mandate that have been successfully completed during the past two terms. Additionally, the IOM report provides potential examples of regulatory progress in epilepsy care and this has been discussed.

The IOM Task Force: The NAC has been an active member of the epilepsy specialists IOM subgroup, working on the development of a screening tool for epilepsy.

Recommendations for Future Work

Stigma Task Force: The current work of the Stigma Task Force will be completed by the end of the current NAC term. Dissemination of results is anticipated through manuscript submission to *Epilepsia*, and presentation at the symposium in Montreal 2013. As this Task Force has been highly productive and the work very significant, renewal of this Task Force should be strongly considered for the next term.

Education Task Force: The PECA program has funds remaining, with a possibility of renewal by UCB. It is therefore anticipated that this program will continue into the next term. The focus of the program (professorships vs reverse visits) should be decided by the new Task Force members. Dissemination of results includes local publications related to each visit, and a manuscript in process. The future of the AES translation program will be decided after the upcoming AES meeting, where usage of the translation headsets will be monitored and compared to the previous year. It is anticipated that if this is a successful project, the cost going forward should be shared with AES.

- **Task Force on Regulatory Harmonization:** 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 (the PEACE meeting) 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 early 2013 will help to direct these efforts.

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Caribbean Task Force: It is anticipated that the Epilepsy Society of the Caribbean will be ratified as a full Chapter member of the NAC in Montreal 2013. The NAC will help the new Chapter to publicize this across the Caribbean. The formation of this Chapter will enable a more unified effort for epilepsy education and clinical care across the English-speaking Caribbean, planned for the next term. The next regional epilepsy Congress is being planned for St Lucia in 2014.

Hispaniola Task Force: In March 2013, the Haiti visiting faculty plans to move to the southern region of the country, possibly Jacmel or Les Cayes. It is anticipated that this work will continue into the next term. The outcomes of this project will be included in the Education Task Force manuscript on the PECA program. We anticipate that Phase 2 of the cysticercosis project will result in significant findings to be published and improve awareness of the prevalence of cysticercosis in the area.

PAHO Task Force: 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.

IOM Task Force: It is anticipated that the NAC will continue to participate closely with the IOM healthcare provider group into the next term. It is recommended that the members of the next NAC consider the IOM recommendations when evaluating possible projects for the Commission to undertake during the next term.

Reported by
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