

COMMISSION ON NORTH AMERICAN AFFAIRS



Sheryl Haut

Members

Sheryl Haut (USA), Chair
Nathalie Jetté (Canada), Secretary
Jose Cavazos (USA), Treasurer
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Peter Carlen (Canada)
Dave Clarke (USA/Caribbean)
Vicente Iragui (USA)
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AES President, Amy Brooks-Kayal (USA)
CLAE President, Nathalie Jetté (Canada)

Subcommissions and Members

Education Task Force

Epilepsy 101 Program - Sheryl Haut (Chair) and members: Howard Goodkin (co-chair), Ed Bertram and Elson So

Intercommission Educational Outreach

Jose Cavazos (Chair) with members Jaideep Kapur, Peter Carlen, Lionel Carmant, Amza Ali, Jorge Burneo and Sheryl Haut

Harmonization of Regulatory Activities

Jacqueline French (Chair) with international members Alexi Arzimanaglou (France), Emilia Bagiella (Columbia), Michel Baulac (France), Meir Bialer (Israel), Rusty Katz (USA), Patrick Kwan (Australia), Scott Mintzer (USA), Jack Pellock (USA), Emilio Perucca (Italy), Steven Schachter (USA) and Eugen Trinko (Austria)

Leadership Development Task Force

Jaideep Kapur (Chair) and Sheryl Haut (co-chair) with members Jacqueline French, Samuel Wiebe, Patricia Braga (Latin American Commission), Amadou Gallo (African Commission), C.T. Tan (Education Commission) and Marco DeCurtis (LASSE)

Caribbean Task Force

Initial Board: Dave Clarke (President) and members (all from Caribbean) Amza Ali, Remy Bellance, Mesha Gay-Brown, Tamika Haynes-Robinson and Morris Scantlebury.

Newly Elected Board (during this period): David Corbin (President), Remi Bellance (Vice-President), Tamika Haynes-Robinson (Secretary), Peter Kowlessar (Treasurer), Natalie Dick, Paula Lashley and Dave Clarke (immediate past president)

Hispaniola Task Force

Lionel Carmant (Chair)

Stigma Task Force

Nathalie Jetté (Chair) and the following international members: Amza Ali (Jamaica), Joan Austin (USA), Helen Cross (UK), Tarun Dua (Switzerland), Patricia Braga (Uruguay), Gretchen Birbeck (Zambia), Hanneke de Boer (Netherlands), Paula Fernandes (Brazil), Sheryl Haut (USA), Kirsten Fiest (Canada), Ann Jacoby (UK), Diane Lorenzetti (Canada), Janet Mifsud (Malta, IBE), Solomon Moshé (USA), Karen Parko (USA), Manjari Tripathi (India), Samuel Wiebe (Canada)

PAHO Working Group

Sheryl Haut and Vicente Iragui (Co-chairs)

Aims

The commission established a number of task forces and working group to accomplish its stated goal, in line with the following ILAE goals:

- 1) ILAE shall serve all health professions as the premier international resource for current and emerging knowledge on epilepsy prevention, diagnosis, treatment, and research.
- 2) ILAE shall serve as an international information resource and leader for optimal, comprehensive epilepsy care.

Commission Activities

June 2013 through June 2014

Education Task Force

Epilepsy 101 Program – This program, supported by the NARC and the AES, aims to reach non epilepsy trained providers (physicians, nurses, allied health professionals) and introduce them to introductory concepts in the diagnosis and management of epilepsy. The focus this past year was to translate the slide set into Spanish. This was accomplished by our colleagues in Latin America.

Recommendations for Future Work

Copyright issues and revenue generation strategies (to ensure sustainability) will be finalized and dissemination will begin.

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Intercommission Educational Outreach

The PECA program continues to support partnerships between epilepsy centers in the Americas to promote education and improvements in epilepsy care. In the current year, 5 programs were established or continued in Costa Rica, Panama, Peru, Ecuador and Mexico. Several of these programs were successful in obtaining funding from external sources to support or supplement these partnerships.

Recommendations for Future Work

Copyright issues and revenue generation strategies (to ensure sustainability) will be finalized and dissemination will begin.

Harmonization of Regulatory Activities

The Task Force on Regulatory Activities has been very productive this past year. This is a task force in collaboration with the European Commission. The goal of this effort is to identify and refine optimal clinical trial methodologies for new anti-epileptic drugs. The task force worked on three reports this past year (submitted or to be submitted) including: (1) A paper on a unified indication (incorporating both monotherapy and polytherapy) for epilepsy was written; (2) The PEACE (pediatric extrapolation academic consortium in epilepsy) initiative has been working with the FDA and has been preparing a paper related to this issue; (3) A paper on time to baseline seizure frequency as an add-on study design was also started.

An AES town hall was held with many members of the FDA addressing the work of this task force, mostly focusing on time to baseline seizure frequency as an add-on study design. There were differing opinions expressed from participants. The FDA is still willing to consider time to seizure as an outcome. The task force and relevant stakeholders met in Prague at the European Commission meeting and also met at the annual AED development meeting in May 2015.

Recommendations for Future Work

A joint US-European meeting is planned in Prague for 2016 to continue the momentum of this important initiative.

Leadership Development Task Force

The North American Commission designed the ILAE Leadership Scholarship Program under the direction of Course Directors Sheryl Haut and Jaideep Kapur. To achieve its mission, the ILAE needs strong leaders who can start and grow new chapters that engage

members; lead global, national and local advocacy efforts; advance research agendas and clinical care for epilepsy patients and recruit young talent to the field. The skills required of these leaders are rarely addressed in graduate and medical training programs. This training gap was addressed by the leadership course.

A class of 21 impressive participants representing every ILAE region enrolled in the 2-day training program that included a networking lunch with the ILAE Executive Team. There were sessions on strategic planning, financial planning, scientific communication, electronic communication, conflict resolution, how to run an effective meeting, and personal leadership style among others. Evaluations and feedback from participants and faculty were incredibly positive. The Leadership Program has successfully completed its inaugural year within the allocated budget.

Recommendations for Future Work

Plan for next program in Barcelona in 2017 and expand the program to provide more advanced applied learning and skill building sessions and networking and mentoring opportunities for ILAE's most prominent rising leaders.

Caribbean Task Force

The Caribbean Epilepsy Society held Epilepsy Week in Antigua from November 9-13, 2015 with teams from the University of Texas (Austin) and New York University. During this week, 106 patients were seen in clinics and this included neuropsychology assessments and plans for optimization of future clinics. Data collection from epilepsy and quality of life questionnaires for research purposes are under way. There were also educational sessions with community, nurses and physician talks. All were very well attended and interactive.

Two publications were generated from this task force:

- Melbourne-Chambers R, Clarke D, Gordon-Strachan G, Tapper J, Tulloch-Reid M. The UWIMONA Paediatric Epileptic Seizure Screening Questionnaire for use in a Resource Limited Setting was found to be valid and reliable in a pilot study. *J Clin Epidemiol.* 2015 Sep;68(9):988-93
- Kruass G, Sandy S, Corbin D, Bird-Compton J, Jack F, Nelson B, Jalonen T, Ali A, Fortune T, Clarke DF, Okolie J. Epilepsy Care in the Southern Caribbean. *Epilepsy Behav.* 2015 Aug 21;51:267-272.

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Recommendations for Future Work

Plans are under way for the 5th NARCCE meeting March 3-5, 2016 in Barbados with stellar speakers from North America and the Caribbean. The group will continue their work to improve education and clinical care in the Caribbean.

Hispaniola Task Force

In 2014-2015, the Haiti portion of this task force was highlighted by the opening of a third site in the city of Jacmel in the southern portion of the island. A family physician and an EEG technologist/nurse were trained and now run the program under the mentorship of a neurologist. They also launched their website www.clidep-haiti.com or www.clidep.org and have recruited medical students to their program.

The most compelling story of this task force is that in the very short time since the epilepsy care centers were created, more than 5,000 people living with epilepsy in Haiti have been seen and are now followed. The clinics continue to face serious treatment gap issues because they do not have sufficient AEDs for everyone (many cannot even afford phenobarbital and therefore have breakthrough seizures when they run out of their medications). Only the Mirebalais site has free access to medication via the NGO Partners in Health. The PAHO program for access to medication is not in place in Haiti.

In the Dominican Republic, the study of controls with no history of epilepsy has started. As of end of November 30, out of 100 patients were recruited and tested. Preliminary results are pending. We remember the first part of this study where in patients with epilepsy, more than 25% were affected by neurocysticercosis and those affected had a high family history of epilepsy. This has led to the development of a parallel project funded by the Dominicans, where they are looking at the role of genetic markers of inflammation in the patients with neurocysticercosis and epilepsy. It is expected that recruitment and analysis of this cohort will be completed by the end of 2016.

Recommendations for Future Work

Part 2 of the the neurocysticercosis project (prevalence in controls) will continue and is expected to be completed at the end of 2016. Dr. Lionel Carmant will be leading fundraising activities in Haiti and in Montreal. A group of colleagues of Dr. Carmant's also plan a 3-day training session in the region (Drs. Anne Lortie, Dang Nguyen, Alexander Weil and Sylvain Chouinard).

Stigma Task Force

The Stigma Task Force is continuing its work on synthesizing the worldwide evidence on stigma in epilepsy. This past year the members worked on data abstraction (in duplicate) of around 300 manuscripts. Two papers are ready for submission – one summarizing validated scales to measure stigma in epilepsy and one summarizing the evidence around interventions to address stigma in epilepsy. These will be submitted as companion papers with the final two papers addressing frequency of stigma and factors associated with stigma.

Recommendations for Future Work

It is expected that all four papers synthesizing the evidence surrounding stigma in epilepsy will be completed by June 2016. These will highlight gaps in the area of stigma in epilepsy research and provide recommendations for future research.

PAHO Working Group

This group highlighted the importance of epilepsy educational programs in Latin America, and collaborated with Latin American members to translate the ILAE educational slides for implementation in Latin America. An "Epilepsy Week" with educational symposia, public education and broad exposure to the local media was organized in Bolivia (Dr. Camargo). A number of other educational programs were also developed in Honduras (Dr. M. Medina) and in Chile (Dr. T. Mesa).

Recommendations for Future Work

Perform an inventory of existing educational programs/resources to avoid duplication of efforts, define educational goals for different levels of health care providers and the public, and explore teaching methods and venues. The group is proposing piloting the final educational program in 2-3 countries before widespread dissemination.

AES, CLAE and CES Activities

Please see separate annual reports for each of these chapters for their respective activities.

Report by
Sheryl Haut