

COMMISSION ON NORTH AMERICAN AFFAIRS



Sheryl Haut

Members

Chair	Sheryl Haut (USA)
Secretary	Nathalie Jetté (Canada)
Treasurer	Jose Cavazos (USA) Jaideep Kapur (USA) Peter Carlen (Canada) Dave Clarke (USA/Caribbean) Vicente Iragui (USA)
AES President	Elson So (USA)
CLAE President	Nizam Ahmed (Canada)
MC Liaison	Samuel Wiebe (Canada)

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 Nizam Ahmed, Lionel Carmant and Peter Carlen

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 Trinkla (Austria)

Leadership Development Task Force

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

Caribbean Task Force

Dave Clarke (Chair) and members (all from Caribbean) Amza Ali, Remy Bellance, Mesha Gay-Brown, Tamika Haynes-Robinson and Morris Scantlebury

Hispaniola Task Force

Lionel Carmant (Chair)

ICD-11 Working Group (NARC in collaboration with Classification Commission)

Donna Bergen (Chair) with international members Ettore Beghi (Italy), Dale Hesdorffer (USA), Nathalie Jetté (Canada), Marco Medina (Honduras), Solomon Moshé (USA) and Sameer Zuberi (UK)

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), 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) and member Samuel Wiebe

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

Mission of the Commission

n/a

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 finalize the

COMMISSION ON NORTH AMERICAN AFFAIRS *(continued)*

teaching materials (slides) for the program and begin to examine options for financial sustainability. This has been completed.

Recommendations for future work

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

Intercommission Educational Outreach

The PECA program has continued to support partnerships between epilepsy centers in the Americas to promote education and improvements in epilepsy care. In the current year, 5 programs have been established or continued in Costa Rica, Panama, Peru, Ecuador and Mexico. Some of these programs had more than one visit this past year (e.g. Peru) with matching funds obtained from another source.

Recommendations for future work

More visits are planned for 2014-2015. The 6P model will be considered (patient, program, practice, publications, policy, partnerships) to evaluate outcomes of the PECA program.

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.

Recommendations for future work

A face to face meeting was planned with key stakeholders (regulatory representatives, task force members and observers) in July 2014 where the three topics written as papers were to be discussed. The three papers will be finalized in 2014-2015.

Leadership Development Task Force

It is important for non-profit organizations to demonstrate strengths and one way to do this is to incorporate leadership development in their strategy. The NARC thus created this task force to contribute to the leadership training of junior/early mid-career academics. This past year, a leadership development consultant was hired to assist in developing the program and a needs assessment was done (sent to ILAE leaders and chapter members). The results of the needs assessment are pending.

Recommendations for future work

Engagement of other commission will be a priority. Nominations for candidates for this program will be sought. Program will be finalized (along with faculty). The first program will be held at the IEC meeting in Istanbul in September 2015. Pre and post evaluation forms will be developed to ensure outcomes are evaluated.

Caribbean Task Force

The Caribbean Epilepsy Society held its 4th biennial meeting in St. Lucia. The meeting was a success. The task force succeeded in obtaining an EEG machine (donated from Global Diagnostics) for St. Lucia. They have also implemented some clinical care audits in a variety of centers. News and media initiatives took place in 2013-2014 to address epilepsy misconceptions with the general public. The task force also lobbied for new AEDs to be available at no cost to patients and they were successful in getting several AEDs on the formulary. A social driving initiative was also created in collaboration with the International Foundation of Applied Disability; the aim of this initiative will be to go to government to, lobby for new laws for drivers with epilepsy.

Recommendations for future work

They will continue to work on the initiatives discussed above. Recruitment of additional epilepsy trained providers will continue to fill gaps in clinical care.

Hispaniola Task Force

In 2014, a second regional epilepsy center was added in Haiti. 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. The clinics have been so successful that they are now facing treatment gaps issues because they do not have sufficient AEDs for everyone.

COMMISSION ON NORTH AMERICAN AFFAIRS (continued)

Recommendations for future work

More clinics are planned for 2015 including one in Jacmel where Dr. Carmant and others will be installing an EEG machine, and doing further training (refresher course) in all the centers. Neurosurgery will also be introduced. Part 2 of the the neurocysticercosis project (prevalence in controls) will be initiated.

ICD-11 Working Group (NARC in collaboration with Classification Commission)

This new working group was established in 2013-2014 with the aim of preparing a document addressing conversion from ICD-9-CM in the US to ICD-10. The group met on a few occasions (IEC Montreal 2013, etc.) to discuss the paper and completed its task. The paper is called: ICD coding for epilepsy: Past, present and future—a report by the International League Against Epilepsy Task Force on ICD codes in epilepsy. It is in press in *Epilepsia*.

Recommendations for future work

A smaller working group created before this larger working group (E. Beghi, D. Bergen and N. Jetté) continue to collaborate with the WHO in ensuring that the upcoming ICD-11 is in line with the ILAE revised terminology and concepts for the classification of seizures and epilepsy. They also continue to be involved in the planning of the field testing comparing ICD-10 to the new ICD-11 codes.

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 have been in progress this past year— one summarizing validated scales to measure stigma in epilepsy and one summarizing the evidence around interventions to address stigma in epilepsy.

Recommendations for future work

This upcoming year, the third manuscript, summarizing the evidence around the frequency of stigma and factors associated with stigma will be completed, along with the two other manuscripts which were started in 2013-2014. Abstracts summarizing this work will be submitted for the IEC meeting in Istanbul.

PAHO Working Group

Drs. Wiebe and Haut attended the PAHO meeting in Santiago, Chile in August 2013.

Recommendations for future work

Future initiatives which are being examined include primary care programs in Santa Cruz, Bolivia; Center of Epilepsy for LA in Chile; and a center in Honduras. They are also interested in developing educational programs for nurses and will consider using the Epilepsy 101 program to avoid duplication of efforts.

The North American Commission

Symposium in collaboration with the European Commission was held at the American Epilepsy Society meeting in Washington in December 2013. The symposium was chaired by S.Haut/N. Jetté and M. Bialer. Topics included: (1) Setting standards: International collaboration for pediatric epilepsy surgery through the ILAE (G. Mathern, USA); (2) International pregnancy registries: A global approach to a global challenge (T. Thomson, Sweden); (3) International clinical trials—threats and opportunities (E. Trinkla, Austria); and (4) Epilepsy, big data and international research (B. Litt, USA).

Recommendations for future activities

The NAC will run a symposium on pediatric epilepsy neurosurgery at the AES Annual Meeting in Seattle in 2014.

AES, CLAE and CES activities

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

Accomplishments (2013-2014)

See above under “Commission Activities.”

Report by
Sheryl Haut