

Commission on Latin American Affairs

List of Members:

Prof Marco T Medina, Chair, Honduras
Prof Marcelo Devilat Barros, Secretary, Chile
Prof Salvador Gonzalez Pal, Treasurer, Cuba
Prof Patricia Campos, Peru
Prof Alejandro Scaramelli, Uruguay
Prof Henry B Stokes, Guatemala
Prof Elza Márcia Targas Yacubian, Brazil
Prof Esper Cavalheiro, Ex officio member, Brazil

Aims:

1. To promote epilepsy education and research in the Latin American Region.
2. To coordinate academic activities among the ILAE Latin American chapters.
3. To improve the health care of people with epilepsy in Latin America.
4. To provide and promote epilepsy education and research with excellence, quality, efficient and humanistic approach for medical and non-medical professionals in Latin America.

Commission Activities:

1. Latin American Epilepsy Academy (Academia Latino Americana de Epilepsia, ALADE)

On 12 February 2007 during the First Latin American Summer School on Epilepsy (LASSE) in Sao Paulo, an official meeting of the ILAE Commission on Latin American Affairs was carried out, with the participation of: Elza M. Yacubian (Chair, ILAE Education Commission), Marcelo Devilat (Secretary), Henry Stokes, Alejandro Scaramelli, Marco T. Medina (Chair, ILAE Commission on Latin American Affairs), Peter Wolf (ILAE President), Nico Moshe (ILAE Secretary), Esper Cavalheiro (LASSE Director), Fernando Cendes (ILAE Brazilian Chapter President) and Jaime Fandiño F. (ILAE Colombian Chapter President)

During this meeting, the Latin American Epilepsy Academy (also known as ALADE: Academia Latino Americana de Epilepsia) was founded. The proposals from Brazil, Chile, Uruguay and Mexico were evaluated as well as the Rules and Regulations of the Asian Epilepsy Academy (ASEPA) and the European Academy of Epilepsy (EUREPA). Elza M Yacubian and Marco T Medina presented a Strategic Planning project for the ALADE.



Founding meeting: Nico Moshe, Alejandro Scaramelli, Esper Cavalheiro, Marco T. Medina, Marcelo Devilat(standing, from left to right). Elza M. Yacubian, Peter Wolf, Patricia Campos (seated, from left to right)

ALADE Mission: To provide and promote epilepsy education and research with excellence, quality, efficient and humanistic approach for medical and non-medical professionals in Latin America.

ALADE Vision: To be a Latin American Institution, a logistic Branch of the ILAE Latin American Commission and the ILAE Education Commission, established to promote and provide epilepsy education and research, aiming to improve the health care of people with epilepsy in the region.

Goal: The goal of ALAE is to promote epilepsy education and research in the Latin American region in order to improve health care of people with epilepsy.

ALADE Executive Committee: On 8 February 2008 during the Second Latin American Summer School on Epilepsy (LASSE II) in Sao Paulo, Brazil, the Latin America Epilepsy Academy (ALADE) Executive Committee was elected by the ILAE Commission on Latin American Affairs. The members of the ALADE Executive Committee are: Elza M Yacubian, Patricia Campos, Silvia Kochen, Francisco Rubio Donnadieu, Alejandro Scaramelli, Esper Cavalheiro (Secretary) and Marco T Medina (President). They will serve from 2008 to 2011.

Legal Status: In February 2008, Esper Cavalheiro, Marco T Medina and Elza Yacubian signed the ALADE legal status document in Sao Paulo. ALADE has a permanent address in Sao Paulo Brazil as a non-profit organization. ALADE is the educational arm of the ILAE Commission on Latin American Affairs.

ALADE LOGO:



Inaugural ALADE Activities: During the Vth Latin American Epilepsy Congress in Montevideo, Uruguay, 5 – 8 November 2008, successful inaugural academic ALADE activities took place. The following educational courses were organized: Neurobiology, epilepsy surgery, electroencephalography, Video-EEG in adults and children and, Clinical Trials.

On 10 February 2009 during the 3rd Latin American Summer School on Epilepsy course, in Sao Paulo, Brazil, the members of the ALADE executive committee: Elza Yacubian, Silvia Kochen, Patricia Campos, Alejandro Scaramelli, Francisco Rubio Donnadieu, Esper Cavalheiro and, Marco T Medina discussed, evaluated and approved the ALADE strategic planning for 2009 to 2011. Dr Fulvio Alexandre Scorza was appointed as administrative manager.

2. Latin American Summer School on Epilepsy (LASSE)

During 2007 to 2009, three highly successful courses of the Latin American Summer School on Epilepsy (LASSE) were organized at the Santa Monica Hotel and Convention Center in Guarulhos, São Paulo, Brazil. The LASSE Director is Esper A Cavalheiro, and the members of the organizing committee was: Elza Márcia Yacubian, Fulvio Alexandre Scorza, Lineu S. Calderazzo Filho, Luiz Eugênio Mello, Américo Sakamoto, Alexandre Valotta da Silva., João Pereira Leite and Fernando Cendes.

- 1) The First Latin American Summer School on Epilepsy: “Epilepsy: translating basic knowledge into clinical applications”, was organized from 4 – 14 February 2007.
- 2) The Second Latin American Summer School on Epilepsy: “Increasing knowledge and decreasing treatment gap”, was organized from 7 – 17 February 2008.
- 3) The Third Latin American Summer School on Epilepsy: “Epileptogenesis in the developing brain: basis for treatment and prevention”, was organized from 4 - 14 February 2009.

The LASSE courses have been a major success and among them it is important to mention: (a) the hotel location (far from appealing tourist attractions but with good services); (b) teacher’s dedication, commitment and generosity; (c) the program that covered different aspects of basic and clinical epileptology allowing a closer interaction of students from these two areas and (d) the open discussion with contributions of all teachers present at the conference room.

Future LASSE: From 28 January to 6 February 2010, the 4th Latin-American Summer School on Epilepsy (LASSE IV) will be devoted to the comprehension of the sequence of epilepsy-related events in an orderly and time-related manner. The School will emphasize the “timing” parameters at the molecular and the systemic levels essential to understand the physiopathological basis underlying seizures and the evolution of epilepsies. As events with time in biological organisms occur both on a continuous and a periodic basis, special attention will be devoted to the temporal regulation of biological events that could interfere

with the seizure onset as well as with the life-time development of the epileptic syndromes. Special focus will be given to brain development, maturation and aging and to rhythms which govern the organism's life and their influence on epileptic mechanisms, such as the rest-activity and sleep cycles and other processes of circadian and seasonal regulation.

3. Latin American Epilepsy Congresses:

a) The IV Latin American Epilepsy Congress was organized by ILAE and IBE through the ILAE Commission on Latin American Affairs and the IBE Latin American Affairs from 6 – 9 September 2006 in Guatemala City. The Co-Chairs of the Organizing International Committee, Henry Stokes and Martin Brodie and the members of the Scientific Organizing Committee, Juvenal Gutierrez and Carlos Acevedo, ensured that the scientific content was both of a high caliber and reflective of issues relative to the Latin American region. More than 300 participants from all the Latin American countries attended the congress. On 9 September 2006 the Latin American Epilepsy Day was also celebrated.

b) A major success was the V Latin American Congress on Epilepsy held in Montevideo, Uruguay, from 5 – 8 November 2008. The Organizing Committee, included members from ILAE and IBE Latin American Commissions. Representatives from the Executive Committees of both ILAE and IBE, the Epilepsy Care Commission as well as members from the local organizing committee, worked in a close collaboration. The inaugural academic courses organized by the Latin American Academy of Epilepsy (ALADE) were successfully carried out during this congress. More than 600 participants from all the Latin American countries attended the congress.

4. Latin American Epilepsy Surgery Subcommittee

The ILAE Commission on Latin American Affairs with the approval of the ILAE President, Peter Wolf, appointed a new Latin American Epilepsy Surgery Subcommittee. The members of this Subcommittee are: Americo Sakamoto (Chair), Manuel Campos (Secretary), Mario Alonso, Jaime Fandiño, Juan Bulacio and a member from Central America (Costa Rica)

The term of this Subcommittee will be the same as the ILAE Commission on Latin American Affairs. The main goals of this Subcommittee are improving the epilepsy surgery gap in Latin America, promote education and research on epilepsy surgery and, work closely with the Latin American Academy of Epilepsy (ALADE). This Subcommittee is working also with other ILAE Commissions: Therapeutics (Dr Gary Mathern), North America (D. Samuel Wiebe) and Epilepsy Care, mainly on the epilepsy surgery gap project and certification pilot project.

5. WHO/ILAE/IBE Global Campaign Against Epilepsy

a) Demonstration project on epilepsy in Brazil: A successful demonstration project on epilepsy in Brazil was carried out (Li LM et al. *Arq Neuropsiquiatr* 2007). They performed a door-to-door epidemiological survey in three areas to assess the prevalence of epilepsy and its treatment gap. They surveyed a sample of 598 primary health care workers from different regions of Brazil to assess their perceptions of the management of people with epilepsy in the primary care setting. The lifetime prevalence of epilepsy was 9.2/1,000 people and the estimated prevalence of active epilepsy was 5.4/1,000 people. Thirty-eight percent of patients with active epilepsy were on inadequate treatment, including 19% who were taking no medication. Based on this demonstration project a program was started: 1) Establishing referral network, 2) continuous provision of AEDs, 3) close monitoring of epilepsy

management via the notification system (Sistema de Informação da Atenção Básica - SIAB) and 4) continuous education of health professionals.

b) Global Campaign and WHO/PAHO Central American Regional Meeting Representatives from the Pan American Health Organization/World Health Organization, (Victor Aparicio, Jorge Rodriguez, Jose Bertolote) ILAE (Marco T Medina, Henry Stokes) and IBE (Carlos Acevedo) and Central America, Cuba, Dominican Republic and Mexico representatives had a meeting in Tegucigalpa, Honduras on 21 to 23 August 2008 to promote the Epilepsy Global Campaign in the region. Dr Acevedo presented a *Latin America Epilepsy Report* and Dr Bertolote the Spanish translation of the *Neurological Disorders: Public Health Challenges* book. During this meeting a pilot demonstration project was proposed in Honduras and a Regional Consensus on Epilepsy was achieved

6. Education Project with The North American Commission (joint report from the North American and Latin American Commissions)

Members: Sheryl Haut (Leader), Jean Gotman, Nizam Ahmed, Juan Ochoa, Jose Cavazos, Marco T Medina (Latin American Commission), Elza Yakubian (Education Commission).

The North American and the Latin American Commissions of the ILAE have joined forces in their commitment to improve the quality of epilepsy care in Latin America. The primary vehicle used is improvement in the transfer of knowledge. Accordingly, the group has designed and is beginning to implement a three-level plan:

Level One: Selected epileptologists from the North American Region, knowledgeable in Spanish or Portuguese have visited medical centers in Latin America for one to two weeks. They were active in regional epilepsy meetings and spending time in epilepsy centers, teaching clinically and didactically, as well as participating in clinical discussions. The intent is to reach as many health care providers as possible. Under the leadership of Dr J Cavazos, this component of the educational initiative has received funds from an unrestricted grant from the USA pharmaceutical industry.

Level Two: Medium term relationships will be established between North American and Latin American Commissions for exchange of information, primarily through electronic means, including video conferencing and particularly web-based exchanges and telephone conferences. This could include clinical aspects, training issues, and other case-based discussions.

Level Three: A long-term relationship will be established between North American and Latin American centers, possibly spanning from one-three years, involving training at the North American centre of a number of staff and personnel from the trainee center in Latin America.

The Latin American Commission (through ALADE) is participating actively throughout the process, and providing feedback in terms of results and direction of these educational initiatives. The first level already started in the following countries: Peru, Panama, Costa Rica, Ecuador and Mexico. Funds for the Visiting Professorships from 2008 to 2012 have been received and are in an account at the AES. Overall, the programs have been very successful.

7. Island of Hispaniola (Haiti) Project (joint report from the North American and Latin American Commissions)

Members: Lionel Carmant (leader, Canada), Marco Medina (Latin American Commission),

Diogenes Santos-Villorio (Dominican Republic), Michel Baldy Mouliner (EUREPA), Alex Elie (Haiti), and Marcel Severe (Haiti).

The thrust of this project was to develop epilepsy clinics/centers in Haiti. Initial groundwork has uncovered a dramatic lack of epilepsy resources and expertise in epilepsy. The initial activities included providing training for technologists and epilepsy nurses from Haiti at a Dominican Republic center. Importantly, the Canadian League Against Epilepsy has been actively involved in this project. External resources being sought involve groups from the USA, Canada, and also a project in collaboration with Dominican region to address the problem of neurocysticercosis. On 4 June 2008, la Clinique d'épilepsie de Port-au-Prince was up and running. The Task Force has identified the most significant needs of the Island: 1) Provide access to proper epilepsy care to the Haitian population. 2) Eradication of neurocysticercosis from the Island of Hispaniola and, 3) Support the development of an Epilepsy Surgery program.

8. *Epilepsia en Español*

The Editor of *Epilepsia en Español* is Prof Natalio Fejerman. This important activity was started in 2006 with the economical support from the ILAE. During 2008 the distribution of *Epilepsia en Español* was improved significantly. Dr Fejerman received favorable comments from many colleagues from the chapters of Latin America and Spain. Marco T. Medina and Elza Márcia Yacubian were included as Co-Editors. An electronic version will be available in the near future, with the support of the pharmaceutical industry.

9. Educational Symposiums

a) Epilepsy Educational Symposium supported by the ILAE Latin American Commission during the Pan-American Neurology Congress Dominican Republic. During the Pan-American Neurology Congress on 7 to 13 October 2007, the Latin American Commission, the North American Commission and the Dominican Republic Chapter organized an Educational Epilepsy Course (on 10 October 2007), with the participation of: Samuel Wiebe (North American Commission, Canada) Lionel Carmant (Canadian ILAE Chapter), Henry Stokes (Latin American Commission, Guatemala), Salvador Gonzalez-Pal (Latin American Chapter, Cuba), Marco T Medina (Latin American Commission), Diogenes Santos Viloria, Jose Cabrera and Rosario Gomez (ILAE Dominican Republic Chapter), Franz Chaves-Sell (ILAE Costa Rican Chapter), Antonio V. Delgado-Escueta and Diana Kraemer (USA).

b) During the International Epilepsy Congress, in Singapore on 10 July 2007 the IBE and the ILAE Latin American Commission organized a session on Complementary and Alternative Therapy for Epilepsy with the participation of Dr Lilia Nunez (Mexico), Alicia Bogacz (Uruguay), Franz Chaves-Sell (Costa Rica) and Marco T Medina (Honduras)

Accomplishments:

1. The Latin American Academy of Epilepsy (Academia Latino Americana de Epilepsia, ALADE), founded on 12 February 2007, in São Paulo Brazil.
2. Latin American Summer School on Epilepsy (LASSE).
3. Successful Latin American Epilepsy Congresses in Guatemala (2006) and Montevideo (2008).
4. Creation of the Epilepsy Surgery Sub-commission.
5. Successful Global Campaign regional activities.
6. Establishing a Collaborative work with the ILAE North American Commission.

Recommendations for future work:

- 1) Continuous support to the Latin American Epilepsy Academy (ALADE) and the regional educational activities (i.e., Mesoamerica and Caribbean, Andean, etc).
- 2) Support to LASSE as an important educational activity.
- 3) Improve basic and epidemiological research.
- 4) Improve the epilepsy care in Latin America (i.e., neurocysticercosis project, epilepsy surgery gap and treatment gap).
- 5) Support to the Latin American congresses. The region needs to improve the financial support for the long term sustainability.

Summary: Based on this team work, the ILAE Commission on Latin America affairs took a big step forward, becoming a mature region: with the foundation of the Latin American Academy of Epilepsy (ALADE); periodical and successful regional epilepsy congresses; the successful Latin American Summer School on Epilepsy (LASSE); establishment of new sub-commissions, like the Epilepsy Surgery Sub-commission, successful Global Campaign regional activities and, the collaboration with the ILAE North American Commission. We still have several challenges in order to improve epilepsy health care, research and education in our region.

Prof Marco T. Medina
Chair