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## ALADE (Academia Latinoamericana de Epilepsia) Task Force

A new ALADE commission was elected in 2019:

Franz Chaves Sell (Costa Rica), President  
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## YES - Young Epileptologists

Johann Sebastián Ortiz de la Rosa (Colombia)  
Viktor Navarrete-Modesto (Mexico)

## Academia Latinoamericana de Epilepsia (ALADE)

### Annual Fellowships

The call for the annual fellowships of the ALADE was made for all chapters of ILAE Latin America through the website of the ILAE. Overall, 16 candidates from nine different

countries applied for the fellowships. The candidates were evaluated based on a set of preestablished criteria (CV, country of origin, commitment to return to their home country after finishing the fellowship, etc.). The three candidates that obtained the highest score were selected for the training, receiving financial support.

### Itinerant Courses (“in-situ”)

ALADE organizes itinerant courses in different locations throughout Latin America. Additionally, pre-convention courses are also held.

In 2019, the ALADE itinerant courses were held in the framework of Epilepsy Weeks in Paraguay, Bolivia, and El Salvador. The ALADE courses supported a larger inclusion of subjects related to epilepsy and provided the opportunity of the presence of epileptologists.

The first ALADE course was held in Paraguay on April 11, 12, and 13, 2019. Topics were the new classification of epilepsy and seizures, semiology and video-EEG, EEG and neuroimaging in epilepsy, rational use of new AEDs, and non-pharmacological treatment alternatives, with lectures by Roberto Caraballo, Fernando Cendes, Alejandro Scaramelli, Marco T. Medina, Mario Alonso, Luis Taboada, Mario Camargo, and Franz Chaves.

The second ALADE itinerant “in-situ” course took place on June within the framework of the Epilepsy Week in Cochabamba, Bolivia in June 2019. There were 59 attendees.

The third “in-situ” course was given in the framework of the first Epilepsy Week in El Salvador on September 4 and 5, 2019. The topic of the course was, “Epilepsy in Primary Care”. It was organized by members of the Commission for Primary Care and endorsed by the ALADE. Lilia María Morales Chacón was in charge of the coordination of the course.

## 13th Latin American Summer School on Epilepsy – LASSE XIII

The 13th Latin American Summer School on Epilepsy was held in São Paulo from March 7 to 15, 2019, at the Hotel and Convention Center Santa Monica.

## ILAE-Latin America *(continued)*

From 218 applications, 61 were selected: 31 Brazilian, nine Mexican, four Colombian, four Peruvian, three Chilean, two Argentine, two Venezuelan, two Guatemalan, two Uruguayan, one Paraguayan, and one Dominican.

On the first day, students were divided into eight groups and a tutor to each group was selected among the LASSE teachers. The group division had the following purposes: preparation of a research project related to the central topic of the School and participation case study sessions.

The School program was fully executed and followed the main theme, "Epilepsy: From Connectivity to the Connectome". An extra class, on request, was given by Dr Marina Bentivoglio on "The Meaning of Scientific Dignity in the XXI Century". On the last day of the School (March 15, 2019), groups of students presented the research projects developed under mentoring:

Group 1: Maternal epilepsy and brain fetus connectivity

Group 2: Connectivity in neurocysticercosis as a model of epileptogenesis

Group 3: Magnetic stimulation for the regulation of hippocampal ictogenesis

Group 4: Dance training modifies brain connectivity in adult patients with pharmaco-resistant temporal lobe epilepsy

Group 5: Brain connectivity changes associated with carbamazepine administration in an animal model of temporal lobe epilepsy (hippocampal sclerosis)

Group 6: Functional and effective connectivity between amygdala and the brainstem in patients with high risk of SUDEP

Group 7: Evaluation of brain connectivity changes in patients with psychogenic non-epileptic seizures exposed to cognitive behavioral therapy

Group 8: Circadian variability of resting-state networks in JME - a functional connectivity study

The discussions that followed each presentation provided an adequate assessment of participants' progress. Many of the teachers present praised the maturity of the discussions and the topicality of the research topics.

Most of the participants emphasized the excellence of

the program by introducing basic physical concepts that facilitated the understanding of the meaning of human connective anatomy, both anatomically and functionally, as well as those related to the concept of effectiveness, especially related to various epilepsy syndromes.

During the meeting of the organizing committee held on March 12, it was decided that the topic of the next edition should be, "Epilepsy Treatment: the State of Art and Challenges," scheduled to take place between February 27 and March 6, 2020.



### Pediatric Epilepsy Training (PET Spanish Version)

PET courses will be available in Brazil and Colombia (from May 2020), and El Salvador (from May 2020).

A pre-congress symposium on the PET will take place in Medellin, Colombia, during the XI Latin-American Congress of Epilepsy.

### Basic and Clinical Research in Epilepsy

The following research studies, started in 2018, are ongoing:

#### *Study on Genetics in Epileptic Encephalopathies*

In the study on genetics in epileptic encephalopathies in Latin-America, coordinated by Dr Iscia Lopes-Cendes from Brazil, data is being collected from centers throughout Latin America. Processing of the data is ongoing.

#### *Study on Cannabis in Epileptic Encephalopathies*

In Argentina, a study on the use of cannabis in epileptic

encephalopathies is being conducted. Public hospitals from throughout the country participate in the study. The two-year trial has entered its second year. The study will be a model for the use of cannabis in other countries in Latin America.

### Fellowship in Epilepsy in Canada

The fellowship under Dr Jorge Burneo at the Epilepsy Program, Western University, London Health Sciences Center, Canada started in 2018.

The fellowship is for a neurologist or child neurologist for the duration of one year with financial support of 50,000 Canadian dollars.

The first fellow has concluded the fellowship, and a call was made to the chapters and on the website of the ILAE for the next fellowship.

### First Symposium: Pediatric Epilepsy and Drug Refractory Epilepsy San Salvador, El Salvador, February 24-27, 2019

On February 24-27, 2019, the first symposium on pediatric epilepsy and drug refractory epilepsy was held in San Salvador, El Salvador.

International guest speakers were Roberto Caraballo, Ángel Hernández and Jorge Vidaurre, and local speakers were Manuel Vides, Claudia Valencia, Ricardo Lungo, and René Silva.

The meeting was endorsed by the International Child Neurology Association (ICNA), Child Neurology Society (CNS), Pediatric Society of El Salvador, and the International League against Epilepsy (ILAE).

The meeting was divided into three sections:

#### *Symposium and medical mission in San Miguel, El Salvador:*

- Part A. Mini epilepsy symposium for pediatricians on 2/24/19. The symposium focused on recognition of common epilepsy syndromes and paroxysmal non epileptic events.

- Audience: Around 70 participants, mainly pediatricians. Supported by the local pediatric society of San Miguel (one of the most important and populated cities in El Salvador).
- Part B. Evaluation of clinical cases with local team on 2/25/19. Patients selected by Dr Rene Silva as Chief Pediatric Neurologist. Cases were selected due to refractoriness and potential for epilepsy surgery. Candidates for surgery were identified.

#### *Symposium and medical mission in San Salvador (capital of the country), El Salvador:*

- Part A. Symposium in pediatric epilepsy and refractory epilepsy on 2/26-28/19.
- Audience: About 120.
- The symposium started with recognition of pediatric epilepsy syndromes and other topics. The second day focused on drug refractory epilepsy and alternatives to therapy including ketogenic diet and surgical options/VNS. Conferences included data about the role of CBD in epilepsy. Clinical cases presented by local neurologists and pediatric neurologists were discussed.
- Part B. Evaluation of pediatric epilepsy cases of difficult control were evaluated by the team at the main hospital (Hospital Benjamin Bloom, the main pediatric hospital in the nation). Many of the cases were candidates for surgical intervention.

A surgical intervention was performed on 2/28 with advice from team members. Most of the surgical candidates were selected for future dates. More cases were evaluated on 2/28/19.

#### *Special symposium for patients and families:*

- Audience: About 65.
- The symposium was addressed to families and patients, in order to understand new evolving concepts in diagnosis and treatment. Panel of speakers discussed different therapeutic options. Questions from family members were answered. Families spent eight hours with panel of speakers.



## ILAE-Latin America *(continued)*



### Meeting of Epilepsy Centers, Santiago, Chile May 16-18, 2019

The first Meeting of Epilepsy Centers was held in Santiago, Chile, on May 16-18, 2019. The central topic of the meeting was cortical dysplasia. Speakers, among others, were Imad Najm, Juan Bulacio, (Cleveland Clinic), Patricia Braga, Daisy García, and Ingmar Blümcke (Germany) with lectures on genetics, pathology, clinical exams and surgery, as well as case discussions.



The meeting was organized following a low-cost model. It was held in a free auditorium, there were no travel costs as the speakers paid for their own tickets, accommodation was at simple hotels, and there were no expensive dinners.

Support from the ILAE (\$10,000) was used for 46 fellowships for the accommodation of LA participants. Additional to ALADE fellowships, there was support from the labs for 100 inscriptions. Forty LA centers participated with 246 attendees.

The plan is to organize this meeting yearly from now on. A special session on the ketogenic diet will be added.

### Epilepsy Weeks in Paraguay, Bolivia, and El Salvador

This year, Epilepsy Weeks were organized in Paraguay, Bolivia, and El Salvador. The IBE and ALADE participated in all three epilepsy weeks.

#### *Paraguay*

Epilepsy Week in Paraguay was held from April 8 to 13, 2019. During the week, there were scientific, social, and cultural activities to increase awareness of epilepsy at the level of public health in different locations in the country.

A scientific international meeting was held for neurologists, neurosurgeons, pediatric neurologists, clinicians, general pediatricians, primary care physicians, medical students, and nurses. During the meeting, three different courses were given: Update in Epilepsy (ALADE), Primary Care in Epilepsy, and Electroencephalography. Additionally, relationships were established with the best epilepsy centers in Latin America.

Different training courses were held for patients, family members, and the general public at the most important hospitals in the country. The week closed with an artistic show, with the presence of authorities who committed to participate actively in the implementation of a national epilepsy program.

Invited speakers were Roberto Caraballo (Argentina), Dr Marco Tulio Medina (Honduras), Dr Alejandro Scaramelli (Uruguay), Dr Franz Chaves (Costa Rica), Dr Mario Alonso Vanegas (Mexico), Dr Fernando Cendes (Brazil), Dr Mario Camargo (Bolivia), Dr Alicia Bogacz (Uruguay) IBE, Laura Cristino (Uruguay), and Eduardo Medina (Uruguay).

There was active participation by the general public.

## ILAE-Latin America *(continued)*



Furthermore, the ALADE course had 59 attendees (specialists), the EEG course had 35 (doctors and technicians), and the course of Primary Care in Epilepsy had 118 (family doctors, young physicians, and medical students).



A media agency was in charge of the dissemination of Epilepsy Week with information for television, radio, the press, and social media.

### **Bolivia**

The first annual epilepsy week in Bolivia was held in 2015. In 2019, the 5th Epilepsy Week took place on July 18-19 in Cochabamba.

This latest edition of epilepsy week in Bolivia in Cochabamba was organized according to the different lines of the project: education of patients and families, reduction of discrimination and stigma in the society, training of primary health-care workers, support from the authorities, and research.

In the framework of education and awareness of the population, including people with epilepsy and their families, there were training courses with educational material in two different cities of the country.

To reduce the stigma, discrimination, and social exclusion of people with epilepsy, a country-wide advertising campaign was held, including a press conference, media tours, distribution of educational material, and the video entitled, "What does it mean to live with epilepsy?".

For health care workers in primary care and medical students, a course was held to improve skills in the diagnosis and management of epilepsy at three different locations in the country.

The need for the creation of epilepsy centers, and the control of quality and prices of antiepileptic drugs was emphasized in a meeting with the authorities. These projects will be supported by PAHO.

Finally, a symposium was held for epilepsy specialists (neurologists, child neurologists, educational therapists, psychiatrists, and EEG technicians) with case discussions and update lectures.



### **El Salvador**

The first Epilepsy Week in El Salvador took place from September 1 to 7, 2019 with a large series of academic and cultural events.

Activities began on September 1 with the first 5KM run for epilepsy, a unique event that attracted more than 150 participants, including doctors, paramedics, patients, and family members --both professional and amateur runners with the goal of raising awareness of epilepsy in the general public.

On September 2 and 3, visits were made to universities and hospitals to give update lectures on epilepsy and its management, and discussion of clinical cases with participation of medical students and residents of internal medicine and neurology. Attendance was over 200 for some of the lectures.

More than 30 specialists participated in the symposium for neurologists, discussing the situation of epilepsy in Latin America and the classification of epilepsy, among other topics.

On September 6, a press conference was held for the media to publicize the national and regional problems related to epilepsy and strategies to address these problems. Simultaneously, at the Tin Marín Children's Museum, playful activities were presented that allowed epilepsy specialists to talk to children about the disease, and what to do when someone has a seizure. The play, "Carlitos and Epilepsy," with a message of non-stigmatization of the disease, was presented to more than 300 children in just one morning.

The courses of Epilepsy in Primary Care and Electroencephalography for Technicians had attendees from across the country: Physicians and family medicine, internal medicine, and neurology residents attended on September 4, and EEG technicians on September 5.

The week concluded with the International Symposium on Epilepsy, which took place on September 6 and 7 and included activities for medical and paramedical personnel, and patients and their families, while a simultaneous EEG meeting was held for technicians.



### Program on Epilepsy Education

On 16, 23, and 30 August, the Program on Epilepsy Education was carried out and addressed to teachers in the three main districts of the Province of Entre Ríos, Argentina — Paraná, Concordia, and Gualaguaychú. The Program was endorsed by the government of the province and the Board of Education of Entre Ríos. The Board of Education handed out a certification and conferred credits for participating in the Program. The Program consisted of lectures on epilepsy in general and neuropsychological aspects of epilepsy, and videos of epileptic seizures in school-age children were shown, as well as a short movie about a pupil with epilepsy during a school camp. Before and after the Program, a questionnaire was administered to evaluate knowledge, attitudes, and practices. For the course, a book entitled, "Epilepsy in the School" was written. In the districts of Paraná, Concordia and Gualaguaychú, 1,600, 1,500, and

1,100 teachers participated, respectively. A PDF version of the book is available on the official website of the Board of Education for all the teachers in the province, as well as on the web site of the ILAE: (<https://www.ilae.org/files/dmfile/Epilepsy-in-the-School---Caraballo-2019.pdf>).

### Latin American Epilepsy Congress (LAEC 2020)

The XI Latin-American Epilepsy Congress will be held in Medellín, Colombia, in May 2020. A comprehensive program is being prepared that will include clinical, educational, surgical, and research aspects related to epilepsy in children and adults.

In addition, the usual symposia for the general public with social and educational items are being organized.

Well-known speakers from both inside and outside the region have been invited.

### Telemedicine

In Salta, Argentina, a symposium on telemedicine and epilepsy was held on September 6, 2019. The meeting was a success; around 300 doctors participated and, through the telemedicine network, doctors from throughout the country were connected during the entire meeting. Dr Sam Wiebe, Roberto Caraballo, Damian Consalvo from the Argentine League against Epilepsy, and several other leading epileptologists as well as local authorities, discussed the most prevalent epileptic syndromes and topics related to the field. Initially, a model of telehealth and epilepsy was presented.

A video was prepared for the meeting to show how the program is working. The video showed the reality of children with epilepsy and their families that live in remote areas without access to care, and how they benefit from telemedicine, mainly regarding care aspects.

Regarding educational activities, currently a program to educate doctors, nurses, and others who work in primary health care is being developed using telemedicine including talks, books, and questionnaires before and after the program, to demonstrate its impact. The program will be implemented in all the Argentine provinces.



## ILAE-Latin America *(continued)*



Several countries in the region (Brazil, Colombia, México) are already working with telemedicine.

Sebastian Fortini (Argentina) was assigned to be coordinator of the Commission for Telemedicine in Latin America.

### Young Epileptologists – YES

Johann Sebastián Ortiz de la Rosa and Viktor Navarrete-Modesto are coordinating the key activities of the YES in the region.

The following activities were developed in 2019:

- The Spanish (Sebastián Ortiz, Colombia) and Portuguese (Patricia Saletti, Brazil) ILAE twitter accounts were launched.
- The ILAE Facebook content was translated into Spanish and Portuguese (Patricia Saletti for Portuguese translation and Helena Franco for Spanish translation).
- ILAE infographics were translated into Spanish and Portuguese.
- YES participated in the Epilepsy Awareness Day in Colombia at the Hospital Militar in Bogotá, Colombia (Paula Martínez Micolta, Juliana Vargas and Manuela Ochoa).
- Elections were held to choose country representatives for YES in Latin America (México, Guatemala, Dominican Republic, Honduras, El Salvador,

Colombia, Venezuela, Ecuador, Chile, Argentina, Brazil, Paraguay, and Uruguay).

- The Latin-American YES group was divided into four internal divisions: Education (Diego Jiménez, Ecuador), Research (Víctor Navarrete, México), Communication (Claudia Cominotti, Argentina), and Advocacy (Manuela Ochoa, Colombia).
- [www.epilepsydiagnosis.org](http://www.epilepsydiagnosis.org) was translated into Spanish (Alejandra Genel from México, Ana Suller from Spain, Carolina Vargas and Sebastián Ortiz from Colombia).
- YES members assisted in case development for the ILAE curriculum (Manuela Ochoa – TLE and Sebastián Ortiz - CAE).
- A Latin American newsletter will be issued (Claudia Cominotti – Argentina).
- A Latin American database for resources and courses was developed (Diego Jiménez – Ecuador and Claudia Cominotti – Argentina).
- There was an official launch of YES country liaisons in the Dominican Republic, Colombia, and México.

Members of the YES are currently participating in the organizing committee of the Latin-American Epilepsy Congress. Additionally, a YES committee was created to plan and develop the YES activities during the the 2020 Latin-American congress.

This committee was divided into three working groups as follows:

- Advertising and promoting our YES events
- Conference planning (submitting proposals and arrangements)
- Local people to establish the networking event and other activities

Different activities have been organized to stimulate young epileptologists to attend the congress and to raise money for the YES. The money that is raised will be used to have one fellowship to the LASSE (Latin American Summer School on Epilepsy).

### Joint activities with local organizations, IBE, and PAHO *Strategy and Plan of Action on Epilepsia of Latin America and the Caribbean 2021-2031*

On Wednesday, June 6, a second video conference was held with Claudina Cayetano (Chief Mental Health PAHO), Jorge Rodríguez (PAHO Consultant), Roberto Caraballo (ILAE Latin America), Carlos Acevedo (Collaborating Center PAHO-Chile), Marco Tulio Medina (Collaborating Center PAHO-Honduras) and Tomás Mesa (IBE Latin America) to organize and plan the next Strategy and Plan of Action on Epilepsia of Latin America and the Caribbean 2021-2031.

This future Strategic Plan will be the guide for the development of future policies and actions in our region, in line with the activities that are being developed at the central level of WHO.

Devora Kestel (WHO) will support this re-accreditation management of the Strategic Plan.

### ILAE-LA Website

Claudia Cominotti, a member of the YES LA, is currently responsible for the ILAE LA website. On the website, all regional and national meetings, congresses, and others scientific activities are announced (<https://www.ilae.org/translated-content/spanish>). Visits from Spanish speaking individuals are increasing.

Report by Roberto Caraballo, Chair, ILAE-Latin America