

ILAE-Latin America

Annual Report 2023

EXECUTIVE BOARD MEMBERS

Mario Alonso-Vanegas (Mexico), chair Guilca Contreras (Venezuela), treasurer Fernando Cendes (Brazil), secretary general Roberto Horacio Caraballo (Argentina), past chair Diego Jiménez-Jiménez (UK), YES representative Silvia Abente (Paraguay) Luis Carlos Mayor-Romero (Colombia) Loreto Ríos-Pohl (Chile) Walter Silva (Argentina)

ALADE Task Force

Patricia Braga, chair Franz Chaves Sell, past chair Damián Consalvo, secretary Fernando Cendes Laura M F Ferreira Guilhoto Iván Gaona Ovidio Solano Silvia Kochen Alejandro De Marinis

HIGHLIGHTS

- Collaboration and coordination focusing on epilepsy awareness and diminishing diagnostic and treatment gaps in epilepsy in the region
 - Epilepsy Week, 3-6 May 2023 in Paraguay
 - XII International Epilepsy Symposium: Committed to epilepsy, 20-21 April 2023 in Santiago, Chile
- Coordination focusing on special topics and regional collaboration, especially in areas with lower resources
 - Symposium on Status Epilepticus, 28 September 2023 in Mendoza, Argentina with guest speakers Eugen Trinka, Samuel Wiebe and Mario Alonso
 - o 1st Academic Meeting in Epilepsy, September 2024 in México and Central America
- Collaboration and coordination focusing on pharmacoresistance and early epilepsy surgery in the region
 - International Symposium on Pharmacoresistant Epilepsy in Infancy: Jornadas de Epilepsia del Golfo de Morrosquillo, 10-11 February 2023 in Colombia
 - o XVI Pan-American Congress on Neurology, 8-10 June 2024 in Lima, Peru

MEETINGS

 During 2023, we had one meeting that lasted six hours during the 35th International Epilepsy Congress (IEC 2023). We had representative participation from 16 of the 19 Latin American countries.



- As regional executive board, we had three meetings via Zoom.
- Individually, the president and secretary met several times during events in the region and Spain, many of those also attended by chairs of other ILAE-Latin American chapters.
- As participants in the Academia Latino Americana de Epilepsia (ALADE), we also met several times via Zoom and had two in-person meetings.

ACTIVITIES

Education

- XVI Latin American Summer School on Epilepsy: Uncertainties in epilepsy, February 2023-March 2024 in Brazil
- Fellowships in epileptology: Three offered, twenty applied
- ALADE Virtual Course on Epilepsy for Primary Care (prior editions 2020, 2021, 2022) *
- ALADE Virtual Capsule on Febrile Seizures (prior editions 2020, 2021, 2022) *
- ALADE Virtual Capsule on First Seizure (prior editions 2020, 2021, 2022) *
- ALADE Virtual Course on Status Epilepticus (prior 2022)
- ALADE Virtual Course: Ketogenic Diet (NEW) *
- ALADE Virtual Basic epilepsy for clinicians (NEW)
- Paediatric Epilepsy Training: PET1 and PET2
 - In April, thanks to ILAE support, thirteen new professionals were trained in three different regions in Brazil
- o PET1: In person, 18 November 2023 in Colombia; virtual, 25 November 2023

*Migrated to ILAE Academy platform

Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders (IGAP)

- 3rd Epilepsy Week, 3-6 May 2023 in Paraguay: Professional medical lectures, and patient/caregiver activities with extensive local participation, as well as IBE and ILAE
- Epilepsy Week in Venezuela (no financial support from ILAE-Latin America, but with extensive participation) and ALADE migrating courses

Bridging Critical Gaps in Treatment

- Epilepsy and Alzheimer's Disease: Challenges for Latin America
 - Workshop supported by ILAE-Latin-America (3,000 USD), ILAE Neurobiology
 Commission (5,000 USD) and International Brain Research Organization (8,000 USD)
 - 132 participants: Argentina (nine), Bolivia (11), Brazil (two), Colombia (34), Cuba (one), Ecuador (one), Great Britain (one), Honduras (one), Mexico (36), Nicaragua (one), Panamá (two), Paraguay (one); Perú (19), Puerto Rico (one), Dominican Republic (four), Spain (four), and Uruguay (four)
- Webinars series to further knowledge of epilepsy and its treatment
 - Neurochemistry- Prof. Dr. Alberto Javier Ramos (Argentina), 6 November 2023
 - o Neurophysiology- Prof. Dr. José Eduardo Peixoto-Santos (Brazil), 13 November 2023
 - Neuropharmacology- Prof. Dr. Luisa Rocha (Mexico), 20 November 2023
 - o Ictogenesis y Epileptogenesis María Elisa Calcagnotto (Brazil), 27 November 2023



ALADE Virtual Courses

• Epilepsy for Primary Care - Registered: 40; completed: 39; approved: 26

• Febrile Seizures - Registered: 24; completed: 24; approved: 18

• First Seizure - Registered: 35; completed: 33; approved: 17

Ketogenic Diet - Registered: 70; completed: 62; approved: 47

Status Epilepticus - Registered: 74; approved: 50

ACCOMPLISHMENTS

The area of primary care and specialized education has undoubtedly been the most successfully developed in the region, with the design and implementation of adequate practical and theoretical based, evaluated courses. The inclusion and promotion of these courses through the ILAE via ALADE has had an impact on the region aiming to ameliorate the lack of professional and specialized education, one of the major regional hurdles to achieving IGAP targets.

Furthering efforts to map out available resources in epilepsy surgery and promoting epilepsy surgery programs was also a major accomplishment during 2023. Data obtained from an electronic survey revealed (zero epilepsy surgery programs in 18 countries) and that this therapeutic option seems to be on the rise, despite still being underutilized, in the region. We have capitalized and strengthen collaborative efforts, for instance by having trained neurosurgeons assist in lower resource regions to initiate surgical programs and including topics of phamacoresistance and early epilepsy surgery in most of the local chapter's congresses.

Even when our efforts have not been sufficient to alter the disparity between individual chapters in terms of accomplishments, and knowing that the mayor challenge faced by our Latin American countries is inequity and inequality in terms of biological, social and health care coverage, we have been successful in coordinating actions and activities in countries that had previously had a lesser development, especially Ecuador, El Salvador, Guatemala, Peru, Venezuela, and partnership with the renewed Cuban chapter.

We consider the increased collaboration with the Pan American Federation of Neurological Societies (PAFNS), Pan-American Health Organization (PAHO) and International Brain Research Association (IBRO) in the development of several symposia a great accomplishment of 2023.

RESEARCH OR ARTICLES PUBLISHED

Conference Paper: <u>Leveraging Policy Frameworks for Epilepsy Advocacy in Latin America: An International Bureau for Epilepsy and Chilean League Against Epilepsy PAHO/WHO Collaborating Centre Multi-Stakeholder Workshop</u>

Poster presentation: <u>A survey of the reality of epilepsy surgery in Latin America</u>, 35th International Epilepsy Congress, 386 (page 167)



ADDITIONAL COMMENTS

We believe that of the great accomplishments and hard work, and since the adoption of the resolution WHA 73.10 on global actions on epilepsy and other neurological disorders to develop an Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders (IGAP), the ILAE has become the academic authority and leadership voice on epilepsy with an increasing role on the social agenda. However, this has not happened in the individual chapters in our Latin American region. At each national level the chapters are lacking the building elements of organizational structure, mandate, inclusivity and representation, outreach and partnership and communications to truly acquire an authority or leadership role. The efforts have been isolated and often lead by individual interests, and we must try to coordinate actions that better serve the optimized use of resources. We have seen a rise in the activities requesting budgets from ILAE; there were six, 12, 20 and 30 such requests in 2020, 2021, 2022 and 2023, respectively. Although this is a step forward, we insist that we need to look to ILAE beyond only requesting budgets and strengthen the mentioned individual building blocks of each chapter to capitalize on previous efforts, other revenue sources, and expertise. Ultimately, we insist that documenting our efforts, publishing, and creating measurable results remains another of our major challenges.



Activities and program during the International Symposium on Pharmacoresistant Epilepsy in Childhood, Coveñas, Colombia, February 2023





Epilepsy Week in Paraguay, May 2023

Participants and instructors, including Mario A Alonso, Roberto Carballo, Carlos Acevedo, Tomás Mesa





Guest speakers: Eugen Trinka, Samuel Wiebe, Mario Alonso

8:15-8:30 - Welcome and opening of the symposium: Dr. Javier Adi and Dr. Beatriz Gamboni

8:30-9:30 - Update on Status Epilepticus: Prof. Dr. Eugen Trinka

9:30-10:30 - New-onset status epilepticus (NOSE): Prof. Dr. Samuel Wiebe

10:00-11:00 Coffee break

11:00-11:45 Non-convulsive status epilepticus in children (speaker to be determined)

11:45-12:30 Non-convulsive status epilepticus in adults: Prof. Dr. Alfredo Thomson, Verónica Campanille

13:00-14:00 Lunch break

14:00-14:45 Treatment of status epilepticus: Prof. Dr. Eugen Trinka

Symposium on Status Epilepticus, Mendoza Argentina, September 2023

On left: Professors Roberto Carballo and Eugen Trinka

Report submitted by Mario A. Alonso Vanegas