

ILAE-Latin America 2022 Annual Report

MEMBERS

Mario Alonso-Vanegas (Mexico), chair
Guilca Contreras (Venezuela), treasurer
Fernando Cendes (Brazil), secretary general
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Silvia Abente (Paraguay)
Luis Carlos Mayor-Romero (Colombia)
Loreto Ríos-Pohl (Chile)
Walter Silva (Argentina)

ACTIVITIES

- Fellowships Epilepsy Research/Treatment Centers
- Funds were awarded for three fellowships
- Latin America epilepsy online course for primary care with 57 registered attendees
- Short virtual courses: 1) First seizure 2) Febrile seizures
- Pediatric Epilepsy Training 1 (PET 1) course in Spanish carried out in Colombia as a three-day “train the trainer” course
- Virtual LASSE 2022 - Epilepsy: Translating basic knowledge into clinical applications
 - Climate change and epilepsy (Sanjay Sisodiya)
 - The epilepsies - the importance of diagnosis (J. Helen Cross)
 - Transition in epilepsy (Jaime Carrizosa)
 - Big Data: From hype to reality (Samuel Wiebe)
 - The subjective side of epilepsy (Peter Wolf)
- Status epilepticus virtual course with 106 registered attendees
- XII Congreso Latinoamericano de Epilepsia
 - LAEC 2023 took place in Medellin, Colombia, on 1-4 October 2023
 - Included a business meeting and ALADE courses
 - A successful collective effort of the ILAE, IBE and scientific committee with the participation of international speakers covering the most relevant issues in epilepsy, from the experiences in basic sciences to the clinical and surgical setting
 - First in-person meeting after the COVID-19 pandemic with a total attendance that surpassed expectations at 300 participants



Images of the XII Latin American Epilepsy Congress, 1-4 October 2022

Epilepsy Week in Paraguay

Highly successful activity in the region aiming to promote national programs in countries where academic and social activities are few, national congresses are not held, and resources are scarce. The aim of this activity was to consolidate within public institutions or agencies, a comprehensive epilepsy program, and provide a space for the participation of patients, families, and caregivers in the decision-making process of people with epilepsy.



Activities during Epilepsy Week in Paraguay, August 2022

Telemedicine

Provide specialized consultations on epilepsy in remote places, used with high success rates success in remote areas of Argentina, it should prove very useful in other countries with similar vulnerable populations or geographic barriers. Experience and results of the project were presented at an international meeting in Ushuaia. Online attendance: 350



Images of the work being done with remote access populations through the telemedicine project in Argentina



Meeting on Epilepsy and Telemedicine in Ushuaia, Argentina, 11 November 2022

ACCOMPLISHMENTS

The prerequisite to achieve the aims and tasks is identifying the people responsible for each chapter and create an effective communication network to share individual needs, prior endeavors, and ongoing work. The region has been characterized by many highly successful nuclei of work, but many have been fragmented and lacked follow-up. Given the challenging circumstances of 2022 freshly emerging from the COVID-19 pandemic all initial communications were online. What became evident is that the great disparity in the composition and management of the different chapters is perhaps the greatest challenge for Latin America. In

fact, we know that Latin America has the highest levels of income inequality and health inequity, with some countries having the highest out-of-pocket expenses in health care. This fact alone is an important limitation for the actions of the board, given it has generated a very different starting point for actions both within countries and among countries. Most chapters have identified the social and economic heterogeneity as the most significant challenge in providing adequate and equalitarian access to best practices and evidence-based information, diagnosis, and treatment. Unfortunately, this also creates a sense of unfairness, and providing the right balance in support becomes tricky. This is exacerbated when financial funds are considered. The first time we did an in-person meeting was during the XII LAEC in Colombia. All 19 chapters received invitations but unfortunately, we only had a 35% attendance. Many important projects were discussed; our efforts should include furthering educational activities for primary health care and specialized education, as well as increasing social awareness programs at the regional level, and concomitantly help develop more locally specific programs that address specific biopsychosocial variables. Interestingly, during this meeting, 20 submissions were presented for funding in 2023, compared to 12 in 2022 and six in 2021.

HIGHLIGHTS

- We requested information from each chapter on the availability of constitution or bylaws, the composition of their respective directive boards, and memberships. We found great disparity in chapters' composition and management. The level of organizational maturity is varied across Latin America. There are chapters with a long standing "tradition" and involvement (Argentina, Brazil, Colombia, Chile, Mexico), some distinguished by the work of highly driven personalities (Cuba, Honduras), and others formally emerging (Bolivia, El Salvador, Ecuador, Guatemala). We should provide support to the more nascent chapters which have larger operational, administrative, and technical gaps. The situation in Peru is of particular interest. The collaborating group expressed, they were only in 2022 handling administrative tasks to establish themselves as the local chapter, updated their status as an association and trying to retrieve their designation as Peruvian chapter. Despite their emerging formal status, they were active both in academic and social awareness events comparable to other chapters. Top-down approaches are unable to meet local demands and needs. Local contexts require a grassroots approach. Thus, certain activities must be left to the individual chapters while others require steering at the Latin America board level.
- A main challenge that is specific to the historical and geo-political circumstances of Latin America we feel must be addressed at the global level is coverage of vulnerable populations, specifically indigenous populations. Efforts have been fragmented or isolated in the past, but there are recent advances. The efforts have included the translation of terminology and didactic material into indigenous languages or dialects (e.g. Tzeltal, Mayan, Mixtecan and Nahuatl), joint work with agencies dedicated to indigenous populations and human rights to ensure adequate understanding of epilepsy, and even incorporation of some traditional or aboriginal remedies to pharmacological treatment.

NEXT STEPS

- In the professional education sphere, we will add two fellowships in epilepsy surgery in the next years and develop a comprehensive detailed curriculum as well as evaluation forms for each of the fellowships offered.
- Analysis of the data gathered by the electronic survey on the practice of epilepsy surgery will be written up in a comprehensive report and will include further cooperation with the Commission on Surgical Therapies.
- The success of the Epilepsy Weeks in Bolivia must be reproduced in other countries. In 2023, it will take place in Guatemala and there is particular interest in developing this strategy in Venezuela.
- Areas or disciplines that are underdeveloped in the region and require concerted efforts include nursing, neuropsychology, neuropsychiatry, and neuropathology.

CHALLENGES AND RECOMMENDATIONS

	ILAE-Latin America	Local chapters
Organizational structure	<ul style="list-style-type: none"> • Structure communication workflows and institutionalize knowledge exchange platforms between chapters. 	<ul style="list-style-type: none"> • Finalize and formalize constitutional bylaws.
Mandate	<ul style="list-style-type: none"> • Delineate the scope and content of global activities targeting vulnerable populations. 	<ul style="list-style-type: none"> • Delineate the scope and content of country-level activities targeting vulnerable populations.
Inclusivity and representation	<ul style="list-style-type: none"> • Ensure equal representation and participation from national constituencies. 	<ul style="list-style-type: none"> • Ensure equal representation and participation from sub-national constituencies.
Outreach and partnerships	<ul style="list-style-type: none"> • Optimize efforts in knowledge dissemination and transfer of lessons learned and best practices by compiling outputs from the local chapters and ensuring the website is up to date. 	<ul style="list-style-type: none"> • Identify and engage stakeholders at the national level and seek alternative funding sources.
Communications	<ul style="list-style-type: none"> • Provide guidelines on internal and external communications (e.g., language, formats). 	<ul style="list-style-type: none"> • Design and launch websites.

Report submitted by Mario A. Alonso Vanegas