

# Chapter Convention Report 2019

## Overview

The International League Against Epilepsy (ILAE) was originally founded in 1909 as an association of physicians and other health professionals with the aim to devote itself to special projects on behalf of persons with epilepsy, and to finding a cure and means of prevention, as well as providing aid and social rehabilitation.[1]

From its beginnings, the League was organized as a central body, with national branches, called “chapters”. Over the years, the number of chapters has grown to 123 chapters, each representing a country. [2]

Between 1992 and 2010, the regional commissions were created for the six world regions - Europe, Latin America, Asia and Oceania, Africa, the Eastern Mediterranean, and North America - as a nexus between the central ILAE and the national chapters. [1,2]

According to the Strategic Plan presented in 2009, the goals of the ILAE are to serve the health profession as the premier international resource for current and emerging knowledge on epilepsy prevention, diagnosis, treatment, and research, to be an international information resource and leader for optimal, comprehensive epilepsy care, to ensure its ongoing organizational and financial viability, and to address and implement thought-provoking and innovative concepts that advance the League’s vision and mission.[2]

Herein, the national chapters play an essential role but may at the same time be the weakest link in the chain, due to lack of resources and poor cooperation from local governments and health care organizations.

The evaluation of the needs of the national chapters is considered important, not only by the ILAE Executive, but also by the different ILAE regions. To obtain information on these needs, communication between ILAE Executive, regions, and the national chapters is crucial.

The Chapter Convention is a classical meeting that takes place during the ILAE International Epilepsy Congress (IEC). In the IEC Congress held in Bangkok in June, 2019, the Chapter Convention was dedicated to evaluate how the ILAE may be able to support the chapters in carrying out the mission and vision of the ILAE community worldwide.

In this session the Executive Committee, the regional chairs, and the chairs of the national chapters came together to discuss different key points in an effort to better understand difficulties as well as examples of best practice of the national chapters. The participants were divided into six different groups in which the following topics were discussed:

- Chapter action plans and advocacy efforts
- Local benefits of ILAE reports
- Possible actions/initiatives/materials from the ILAE Executive that are useful for chapters/regions
- Communication across chapters/regions
- Possible role for ILAE interest groups/sections
- Role of the International Congress for the chapters

## Objectives

The aim of the meeting was to gain feedback from the national chapters with regard to examples of successful activities as well as difficulties encountered.

*The following topics were suggested as guiding points to consider in the discussion:*

- Strengthening effective leadership and governance
- Improving provision of epilepsy care
- Integrating epilepsy management into primary health care
- Increasing access to epilepsy medicines
- Supporting strategies for epilepsy prevention
- Increasing public awareness and education
- Strengthening health information and surveillance systems
- Improving investment in epilepsy research and increase research capacity
- Collaborating with civil society and other partners and stakeholders

Participants in the meeting were members of the management and executive committees and chapter chairs of the ILAE. Each of the six discussion groups was coordinated by two members of the executive committee.

**Group 1 - Chapter action plans and advocacy efforts:** Coordinators Sam Wiebe (President), Roberto Caraballo (Chair ILAE Latin America)

In group 1, action plans and advocacy efforts were discussed around the question: In what ways are chapters advancing the World Health Assembly Resolution (WHA) agenda?

More specific questions were raised with regard to what the chapters were doing to improve epilepsy care, including integration into primary health care systems, what barriers were encountered and how efforts should be focused.

One of the main barriers appears to lie in the difficulty in finding professionals and volunteers who are willing and have the time to dedicate to activities of the League. This scarcity of professionals may lead to an absence of training in epilepsy and insufficient lobbying capacity. The creation of a strong education portfolio which can be readily accessed, as well as the creation and the involvement of strong NGOs or patient organizations, were seen as possible solutions.

The democratic election processes in the chapters was considered important in order to maintain progress and injection of new ideas.

As to the question of what could be done to make epilepsy a priority, it was highlighted that epilepsy is not funded in proportion to other diseases with similar prevalence and impact. Effective communication, a social profile in medical education, and getting people living with epilepsy to become champions to advocate for this condition were considered as possible solutions. Legislation for neurological disorders, epilepsy action plans and strategies, and guidelines for primary healthcare created with direction from the ILAE Executive were also suggested as valuable tools that could improve access to epilepsy care. Barriers to implementation of these type of measures include financial limitations, stigma or lack of knowledge, and the absence of effective communication. Additionally, a lack of partnership with local authorities and universities was a concern.

In many countries there is a lack of well-designed legislation and plans, effective health care systems, and national and regional referral plans. These problems are compounded by geographical issues, such as long distances from care, insufficient support and education for primary care, and a scarcity of proper transition plans from childhood to adulthood care.

Overall, it was noted that data on needs was insufficient at local levels.

**Group 2 Local benefits of ILAE reports** coordinators: Helen Cross (Treasurer) and Angelina Kakooza, (Chair of ILAE – Africa)

In group 2, how ILAE activities may help the efforts of the national chapters was discussed.

Specific questions were how further reach can be gained and how the League's efforts (e.g., publications, courses, meetings) may help address the issues of improving epilepsy care, i.e. what would be helpful.

In the first place it was considered that directions from the ILAE Executive, with the use of the ILAE name helps to move forward the local agenda. Herein standards of care and standards for driving were particularly mentioned.

In general, the name of the ILAE was considered helpful in any search for funding.

It was discussed that regional cohesion is not always apparent and that chapters often feel they are working in isolation. In some countries the difference between the ILAE and the International Bureau for Epilepsy (IBE) is unclear, leading to confusion within countries about which organization an individual may align with, especially when the name ILAE is not used in the name of the chapter organization.

For many chapters it would be useful if journals became more accessible as subscriptions are currently still prohibitive in some parts of the world.

The discussion however centered on two large topics: Advocacy and education.

There was a general belief that epilepsy is lagging behind other diseases with regards to public awareness and advocacy. International epilepsy day was considered a good idea, but the timing may be difficult in some geographical areas. For example, the second Monday of February clashes with the Chinese New Year, and therefore a different date might be preferable in some cultures.

The importance of advocacy training was highlighted; for example, how best to advocate and how to interact with the public/politicians, with the availability of online training materials and/or tools. Additionally, better use of social media, such as You Tube, and improved links to other websites available through the ILAE office and chapter websites, with regular updates was suggested. It was noted that duplication of efforts could be avoided with centralization of material.

With regard to education, the ILAE epilepsy curriculum was much welcomed. It was considered however that there is a need for standardized teaching materials that can be used globally. On this line, there is a need to review existing courses and support the regional efforts in developing standardized teaching programs modeled on those that exist. The development of standardized teaching modules with flexibility for regional adaptation was suggested.

**Group 3 – Possible actions/initiatives/materials from the central ILAE that are useful for chapters/regions** coordinators Ed Bertram (Secretary General) and Akio Ikeda, (Chair of ILAE - Asia Oceania)

In Group 3, discussion was around what actions/initiatives/materials the ILAE should undertake that would be seen as a priority for the chapter or regions. The central question was how chapter, regional and League educational efforts should be organized to help address WHA goals.

Suggestions for interventions from the ILAE Executive that would be useful for the chapters or regions were divided into three domains: 1. Standardization and approval; 2. Information sharing; and 3. Communication and collaboration.

1) Standardization and approval

It was suggested that the ILAE Executive should play a role in the development and sharing of strategies to overcome prejudice and stigma as well as programs to increase knowledge about epilepsy. They should additionally guide the establishment of more uniform safety laws, for example on driving and work settings. It was suggested that a process should be in place for the ILAE to review and approve or endorse national epilepsy guidelines so that the guidelines have the seal of approval of the League.

2) Sharing the information

Another important role of the ILAE Executive that was suggested was in providing the opportunity for members and chapters to share experience with one another about how to work with governments. Similarly, the ILAE Executive could develop and share strategies to improve access to government for chapters and epilepsy groups, and also create and share general epilepsy standards of care that chapters can modify to adapt to their national situation. The ILAE Executive could facilitate the sharing of knowledge about national rules for access to medications so that members understand potential barriers and can develop strategies to improve access.

In addition, participants believed that further resources for individuals on how to run a chapter would be useful particularly for new leaders, as well as a forum where chapter leaders could share their experiences about solving problems and about how to create and achieve their chapter goals.

3) Communication and collaboration

It was suggested that a role of the ILAE Executive was to create epilepsy programs for primary care providers and develop a forum to share national experience. There should be uniform templates for education in primary care in epilepsy that all chapters could use, translate, and modify. Basic teaching packages could be developed as part of the template. A course on how to work with patient organizations would be important.

**Group 4 – Communication across chapters/regions** coordinators: Emilio Perucca (immediate Past President) and Chahnez Triki, (Chair ILAE-Eastern Mediterranean)

In group 4, it was acknowledged that the ILAE is doing much in creating an international epilepsy community but that communication across chapters/regions can be improved.

The ILAE is seen to be performing well when organizing regional meetings, the website, the development of courses, the publication of journals, the YES group, and the joint collaboration with the World Health Organization (WHO), with the WHO global report as an example.

However, it was suggested that the ILAE could do better with regard to communication. Social media is more widely utilized than websites, and Instagram more than Facebook. The registration fees for congresses are regarded as high, specifically for the International Epilepsy Congress and for younger people. Additionally, a lack of training for primary care providers (at the community level), or nurses was emphasized again.

The following suggestions were proposed:

- Coordinate efforts internationally to uniformly organize international epilepsy day
- More courses outside Europe in collaboration with local chapters
- ILAE sponsored/standardised courses
- The provision of more travel bursaries
- Support participation of international faculty in low-income national conferences/courses
- Facilitate/promote support of low-income regions by higher-income regions
- Sub-regional meetings within regions
- ILAE certification at differing levels

**Group 5 – Possible role for ILAE interest groups** coordinators by Jean Gotman (Strategic Advisor) and Nathalie Jette, (Chair ILAE North America)

In group 5, the topic was the role of ILAE interest groups to allow people with common interests to come together and share ideas and experiences. The question was whether chapters or regions would benefit from web-based groups that also interact at congresses and whether this would be of benefit clinically or for research. These groups would not work in the same way as American Epilepsy Society (AES) special interest groups, that meet at AES meeting for a symposium but may not communicate between AES meetings; but would be more like the American Academy of Neurology (AAN) epilepsy section where they meet at AAN but also have a newsletter and some communication throughout the year. It was considered that these sections/interest groups would allow people with common interests to get together and share ideas and experiences.

These sections/interest groups would be proposed by any member, but should be proposed through chapters, but the exact mechanism remains to be determined. Coordination would be the responsibility of the section head/co-head; who would organize calls, meetings, etc. The groups would self-organize. There would be support from ILAE for zoom calls, getting a meeting room at a congress, etc. but no additional funding would initially be provided.

If the section wanted to do anything more substantial, they could provide a proposal to the ILAE executive/management committee for consideration to see if funding may be provided. It would be necessary to make sure that sections relating to an existing task force or commission are linked so as not to duplicate efforts. Lines of reporting within the ILAE administrative structure were not discussed.

Examples proposed included a section on how to advance policy/advocacy in the regions, autism and epilepsy, neurometabolomics, etc.

**Group 6 – Role of the International Congress for the chapters** coordinators Alla Guekht (Vice President) and Eugen Trinkka, (Chair ILAE – Europe)

In group 6, the role of the International Congress for the chapters was discussed to evaluate whether the meeting is addressing the needs of the community using a SWOT (strengths, weaknesses, opportunities, and threats) analysis.

The strengths of the Congress include the good program and organization, the diversity and quality of the speakers, education, its social focus, the YES activities, interaction with people living with epilepsy (IBE), and the availability of bursaries.

The following priorities were suggested: education, interaction with colleagues, networking, latest knowledge available (current practice, way to move forward), timing (no clashes with other meetings), economic success, accessibility (safety, reachability, attractiveness), presenting work (science, current practice).

Weaknesses of the International Congress included lack of specification of the target audience, inflexible registration fees (according to gross domestic product (GDP) & other criteria), and the timing (dates not fixed same time of year).

On the other hand, opportunities included improvement of educational program (flexible fees, handouts, evaluation), increased bursaries, hands-on courses, focused tailored networking, teaching tailored to differing situations (e.g. India, Caribbean), speaker support for regional congresses, and increasing number of neurologists/epileptologists.

Finally, financial difficulties in the organization of neurological congresses as well as local meetings, withdrawal of support from the pharmaceutical industry, increased costs, and accessibility issues were seen as possible threats.

### Common themes to the chapter convention

Overall, chapter members highlighted many aspects where ILAE seems to be working well, but also areas where improvements could be made. Table 1 shows the common themes, with limitations/barriers and ways forward that were suggested during the chapter convention.

Table 1. Common themes to the chapter convention

	Limitations	Ways forward
Advocacy	<ul style="list-style-type: none"> <li>• Communication – limited strategies</li> <li>• Duplication of effort</li> <li>• Less prominence than other diseases</li> <li>• Stigma</li> </ul>	<ul style="list-style-type: none"> <li>• Share strategies for improving access to government</li> <li>• Educational initiatives on how to work with advocacy groups</li> <li>• Coordinated efforts with regard to international epilepsy day</li> </ul>
The ILAE as a community	<ul style="list-style-type: none"> <li>• Time availability</li> <li>• Geographical/financial disparity</li> <li>• Lack of available professionals</li> <li>• Lack of consistent democratic processes across chapters</li> </ul>	<ul style="list-style-type: none"> <li>• Certification of level of competency through local chapter</li> <li>• Interest groups</li> <li>• Support of lower income regions by higher income regions</li> <li>• Sharing of strategic plans</li> <li>• Chapter leader events to share experiences</li> </ul>

Regional educational efforts	<ul style="list-style-type: none"> <li>• Lack of partnerships with authorities and universities</li> <li>• Prohibitive subscriptions of journals in some parts of world</li> <li>• Different standards of care/availability regionally</li> </ul>	<ul style="list-style-type: none"> <li>• Strategic planning of congresses; consideration of fees</li> <li>• How to run a chapter</li> <li>• Sub-regional meetings</li> <li>• Standardised teaching materials</li> <li>• Training directed at full range of levels</li> <li>• More travel bursaries/funded exchange initiatives</li> </ul>
Standardisation of service provision – the global agenda	<ul style="list-style-type: none"> <li>• Lack of high quality legislation and plans</li> <li>• Distance/geography from care</li> <li>• Insufficient support for primary care</li> <li>• Ineffective health care systems</li> </ul>	<ul style="list-style-type: none"> <li>• Strive toward globally applicable guidelines that can be adapted to the local context</li> <li>• Position statements</li> <li>• Create programmes to increase knowledge for all health care providers</li> </ul>

National chapters are the means to carrying out the vision and mission of the ILAE, mainly because of their ability to work together with local non-governmental organizations, health care providers and governments.

To support the chapters, close communication among the ILAE Executive, regions, and national chapters is crucial. The meeting in Bangkok brought together members of the management and executive committee of the ILAE and chairs of national chapters to discuss important challenges faced by the national chapters.

Different commissions of the ILAE may be helpful in reaching the objectives discussed.

The meeting was a first step towards the possibilities of face-to-face discussion as a new initiative to raise issues encountered by chapters, and a means of finding a common way forward. This highlighted the benefits of face to face discussion in raising important topics in the regional meetings and supplemented with other means (email, online meetings, etc.) may be a way to improve communication among the chapters, the regions, and the ILAE Executive.

Since the meeting in 2019, the world has been affected by the COVID19 pandemic, changing the outlook to much of what we do. Our management of epilepsy has had to take on a new face, in addition to our patients being affected in many different ways. To what degree the pandemic has affected epilepsy services will not only vary according to region, but there will also be a variability to the longer term affects. The ILAE has sought to continue to collect information as to how clinicians and patients may be affected through surveys available on the ILAE website. The results we hope will guide as to how we may continue to advocate in a positive way for both those who care for patients with epilepsy as well as the patients themselves.

## References

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**Roberto Caraballo, Helen Cross August 2019**



## **Specific Actions for discussion**

### **Advocacy**

Each chapter could be encouraged to propose one priority national advocacy activity. After one year, chapters report and exchange on success and failure, with help from central ILAE.

Creation of an interest group on policy/advocacy as this seems the most prevalent need.

### **ILAE as a community**

Each chapter could define one key document to be generated by ILAE and that would be helpful to the chapter (e.g. driving guidelines, minimal care, availability of medication, etc)

Train chapter leaders, particularly new ones, on how to run a chapter: e.g., develop “buddy system” by pairing one experienced chapter executive with a new chapter executive.

### **Regional educational efforts**

There is a need for courses for primary care providers: could make inventory of existing courses and allow translation or dissemination of such courses.

Development of one ILAE course for primary care providers

### **Communication across chapters/regions**

Discuss sub-regional meetings

Support participation of international faculty in low-income national conferences/courses

Facilitate/promote support of low-income regions by higher-income regions

The high cost of Journals is perceived as prohibitive in many countries. However, this may be mainly a problem of communication as ILAE journals are FREE in developing countries. Communication about League offerings should be improved.