



Welcome to the Young Epilepsy Section!

On-Boarding Package for Establishing a YES National Chapter

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Attachments

ILAE-YES Terms Of Reference

Modifiable Power Point presentation (content: YES overview)

YES introduction video

Template poster (high resolution)

YES logo suite (high resolution)

Template Power Point presentation (no content)

Requirements for Setting up a National Chapter of YES

1. Is it appropriate to set up a National Chapter of YES in my country?

The YES global mission. The Young Epilepsy Section (YES) of the International League Against Epilepsy (ILAE)¹ was founded in 2018 with the aim of improving the professional development of young people in epilepsy, and to deepen the participation of young people in the ILAE for their mutual benefit. ILAE-YES is a world-wide organisation of young people in the early stages of a career focused on the care of people with epilepsy, and/or epilepsy research; this includes clinical and basic scientists, nurses, physicians, students, psychologists, pharmacologists, physicists, mathematicians, and allied health professionals.

Despite its recent origins, ILAE-YES already boasts an international membership of many hundreds of young professionals dedicated to improving the lives of people with epilepsy through cutting-edge research and best clinical practice. The YES diaspora involves all six ILAE regions; namely Africa, Asia-Oceania, the Eastern Mediterranean, Europe, Latin America, and North America. To co-ordinate this diffuse membership and to oversee the organization of regionally accessible YES events, ILAE-YES relies on its six Regional Representatives, who in turn work collaboratively with a network of National Liaisons from their region to ensure that the work of ILAE-YES is translated efficiently and effectively to all of our members, no matter where they are located in the world. Both the Regional Representatives and the National Liaisons are democratically elected by their regional or national constituents at the relevant regional or national chapter congress.

At global and regional levels, ILAE-YES organises a busy schedule of scientific, educational, and networking events throughout the year. Our Task Forces are also highly regarded contributors to many of the ILAE's educational and communications strategies, and we fund and manage numerous bursaries and fellowships so that junior ILAE members may have access to educational opportunities the world over. This work is achieved in a highly collaboratively fashion, with the workload cheerfully taken up by our highly skilled active members and coordinated online to overcome geographic barriers.

The role of a National Chapter. Given the existing, vibrant portfolio of global and regional ILAE-YES events, the need for a specific National Chapter of YES needs to be carefully considered. In particular, are there large numbers of junior epilepsy professionals in your country, who remain underserved in terms of their professional development and engagement despite the activities of ILAE-YES in your region? Some examples of questions to consider include:

- Is a national entity of young epileptologists or similar not yet available?
- Is your current YES national liaison overwhelmed with the quantum of work demanded by their peers in that country?
- Is there a clear need and rationale for a YES National Chapter?
- Have a clear sense of purpose and plan for action been articulated?
- Does your country have a sizeable (>5) team of national contributors with adequate time in their schedule to establish and grow a vibrant National Chapter?
- Is there initial support from the national ILAE chapter president for such an initiative?
- Does the plan have the support of the ILAE-YES Regional Representative?

Do not establish a national chapter if these requirements are not met.

¹ The global organisation of YES will henceforth be referred to as ILAE-YES

The country considering becoming a YES National Chapter needs to have the personnel and monetary capability to be entirely self-managed and self-funded. So as not to dilute the momentum and funding capacity of the global ILAE-YES movement, any National Chapter will be an entity in its own right. Specifically its governance will be independent to that of ILAE-YES and its administration and activities will need to be self-funded (although the non-monetary resources of ILAE-YES may be shared with a National Chapter with the discretion of the ILAE-YES Board; for instance, branding, educational materials, et cetera.). Please note that this means that ILAE-YES also does not have funds to assist with travel costs of national office bearers to attend ILAE congresses. If you require such funding, we suggest that you approach your national ILAE chapter for advice.

Against this background, careful communication and collaboration between and YES National Chapter and the global ILAE-YES organization is paramount to the success of both.

2. Tasks for a YES National Chapter

The roles and activities for a YES National Chapter are distinct from those of a National Liaison (please refer to the ILAE-YES National Liaison Manual if you require further information), and in the case of the establishment of a National Chapter its Chair would take on the role of National Liaison. Potential activities include:

- Organisation of a program of professional development, networking, educational, and scientific activities that support the needs of young epilepsy professionals ages <40 years in your country
 - This must be done in consultation with the President or Chair of your country's ILAE national chapter
- Promote ILAE-YES and the National Chapter on a national level (e.g., national chapter meetings, courses) and encourage active membership in both the global organisation of ILAE-YES as well as the National Chapter
 - This includes raising awareness about epilepsy (advocacy) and attracting young people to epileptology generally
- Collaborate with national "Young Neurologists" or other such existing national chapters of young professionals that intersect with epileptology on advertising educational courses, conferences, bursaries, et cetera
- Partake in the regional ILAE-YES teleconferences as the representative of your country
- Facilitate the on-site organisation of regional or international ILAE-YES events in your country
- Integration of the YES National Chapter with the ILAE national chapter and its task forces, so that the mission and views of junior epilepsy professionals are also represented with the peak national body for epilepsy

3. Chair of a YES National Chapter

In addition to the eligibility criteria previously outlined for a YES National Liaison (see relevant manual), the elected leader of a national chapter of YES will:

- have a **clear sense of purpose** for a YES National Chapter
- draft a strategic plan for a YES National Chapter
- shape the governance of a YES National Chapter in collaboration with the YES National Chapter board
- manage a team of contributors within the YES National Chapter
- chair regular general assembly meetings and democratic elections of the YES National Chapter leadership team

- chair regular meetings of the leadership team (e.g. telephone conferences, business meetings, etc.) to support day-to-day business
- take responsibility for organising activities at the national ILAE chapter meetings or delegate it to a fellow YES National Chapter member
- communicate with the ILAE national chapter executive
- closely communicate and collaborate with the ILAE-YES Board

The Chair must be democratically elected at a general assembly meeting, to be held at the annual meeting of the national ILAE chapter. The relevant ILAE-YES Regional Representative may collate the nominations ahead of the meeting to check eligibility criteria, if appropriate.

4. Process for ratifying a new YES National Chapter

Process for establishing a new YES National Chapter

- Assemble a team of several young collaborators from different regions in your country, specialties, and backgrounds. Please make sure to balance gender, level of expertise, disciplines, and ages (N.B. all members must be <40 years old age in accordance with the definition of a junior member by the ILAE)
- Formulate a rationale for a YES National Chapter
- Approach the relevant ILAE-YES Regional Representative to obtain their support and to discuss further steps
- Prepare a realistic plan and outline aims and outcomes for your YES National Chapter. Can you make a positive impact, above and beyond what is already provided by ILAE-YES and other organisations?
- Outline the governance structure and prepare Terms of Reference for your national chapter. See the ILAE-YES Terms of Reference for guidance
- Approach national ILAE chapter leaders, present your initiative and seek their guidance and support
 - Ultimately, the endorsement of the national ILAE chapter is essential. An email must be sent to the yes@ilae.org email account from the president/chair of your national ILAE chapter, confirming that they approve of the establishment of this official YES national chapter (see documentation requirements below)
- Stage a general assembly meeting at the annual meeting of your ILAE national chapter to discuss and formalise plans for your national YES chapter. Vote to ratify proposed Terms of Reference and elect a leadership team
 - Encourage the participation of as many young people as possible by advertising the general assembly meeting amongst peer networks well in advance of the meeting
 - Consider organising an accompanying programme of events during the ILAE national chapter meeting to increase awareness about YES, for instance a career development session specifically aimed at young congress participants, a booth in the exhibition area, a networking or social event, et cetera. As noted previously, unfortunately ILAE-YES cannot provide financial support of national activities
- Receive formal approval by the ILAE-YES Board (see documentation requirements below). After such approval you will be formally affiliated with YES and allowed to use the YES name and designs (corporate identity, logo, flyer templates, et cetera)

CHECKLIST: Documentation to be provided to the YES Board for national chapter ratification

- ❑ An email to the yes@ilae.org email account from the president of your national ILAE chapter, confirming that they approve of the establishment of this official YES national chapter
- ❑ A one-page document outlining the rationale for the national chapter, as well as its initial goals and vision
- ❑ Minutes from the meeting in which the YES national leader and any other office bearers were elected
- ❑ Birth certificate or similar of the elected leadership team to confirm that they are all <40 years of age

What if my country does not have an ILAE national chapter, can we still establish a YES national group? Yes – but this is a rather rare circumstance that will require close collaboration with the ILAE-YES Board to achieve. Please contact your Regional Representative in the first instance for advice.

5. Communication policies

In line with the independence of a YES National Chapter from ILAE-YES, the national chapter must establish their own methods of communication. Based on the experience of ILAE-YES it is recommended that inter-meeting internal communication takes place on a Slack workspace (or similar web-based messaging application, e.g. Flock), with regular meetings of the leadership team and general membership to occur via Zoom, Skype, or similar web-based videoconferencing application. Face-to-face meetings are encouraged wherever possible, with an annual business meeting to occur at the ILAE national chapter meeting. For external communication, it is recommended that the National Chapter sets up its own email address and curates a national mailing list, with members who sign up to this mailing list given the option that their address is shared with the global ILAE-YES mailing list. The collection and storage of email addresses and member details must be conducted in line with the ILAE's privacy protection policy; please contact the ILAE-YES Communications Task Force leader for advice on this matter.

6. Governance

The governance of a YES National Chapter is independent of the global ILAE-YES movement. A National Chapter needs to formulate and ratify its own Terms of Reference and internal structure at a general assembly meeting. It is strongly suggested that the YES National Chapter is formally represented at the national ILAE chapter, but the detailed arrangements of this relationship will vary from country to country.

At minimum, the formal organisational structure of a YES National Chapter should include a Chair, vice-Chair, Secretary, and Treasurer. Formal delegates responsible for communications, education and mentoring, and scientific programs is also recommended. Of course, the internal governance of a National Chapter can mimic that of ILAE-YES, but should be adjusted according to local needs.

Terms of the affiliation with ILAE-YES. Although a YES National Chapter is independently governed from ILAE-YES, a formal affiliation exists with the global movement. As such, the National Chapter must be viewed as representing the values and mission of the global movement, and as such must behave in line with these values and mission at all times.

In the extremely unlikely scenario that the activities and/or behaviour of a National Chapter contravenes the values and mission of ILAE-YES, the following process will occur in order of escalation or noncompliance:

1. The ILAE-YES Regional Representative will discuss the concerns of ILAE-YES with the Chair of the National Chapter
2. The ILAE-YES Chair will discuss the concerns of ILAE-YES with the Chair of the National Chapter
3. The ILAE-YES Board will issue a formal notice to the National Chapter, outlining the concerns of the Board as well as an invitation for the National Chapter to formulate a plan to resolve these concerns in concert with the Board and/or Regional Representative
4. In the case that a satisfactory outcome cannot be agreed upon and enacted, and the National Chapter continues to contravene the values and mission of ILAE-YES, the Board of ILAE-YES has the power to issue an Extraordinary Motion to revoke the formal affiliation of the National Chapter with ILAE-YES. This revocation will also be communicated to the members of ILAE-YES and the relevant ILAE national chapter, and the National Chapter asked to rebrand their organisation so as to make it clear that it is no longer affiliated with ILAE-YES.