

TERMS OF REFERENCE

Summary

The Young Epilepsy Section (YES) of the ILAE is a world-wide organization 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 other allied health professionals. All ILAE Junior Members (age < 40) qualify as regular YES members and are encouraged to actively support our activities for young epilepsy professionals/students, and to take on tasks organised by the YES Leadership Team.

Our goals are to improve the professional development of young people in epilepsy, and to deepen their participation in the ILAE for their mutual benefit. This includes facilitating peer and mentor support, providing networking and educational opportunities tailored to young people in epilepsy, working to increase their involvement in epilepsy conferences, as well as supporting future leaders of the ILAE and its chapters. It seeks to achieve this using a grassroots-style organisation to effect change at the local, regional, and international levels of epilepsy care and research.

YES is presided by a leadership team consisting of a board, regional representatives, and task force leaders. These positions (with the exception of regional representatives) are elected at the YES biennial general assembly meeting in the context and vicinity of the International Epilepsy Congress. Regional representatives are elected either at the regional ILAE epilepsy congress or at the International Epilepsy Congress. The impact of YES will be measured biennially using hard and soft metrics. All YES Task Forces and YES Regional Representatives will formally report on progress during the YES biennial meeting and written reports will be handed to the ILAE Next Generation Task Force.

1. Name

YES - Young Epilepsy Section

1.1 Initial remarks:

In this document, *epilepsy professionals* are defined as people involved in any aspect of clinical care or research in epilepsy and students. It shall be emphasised that this includes all involved disciplines –

i.e. not only medical clinicians, but also nursing staff, students, neuropsychologists, biologists, physicists, chemists, engineers, mathematicians, etc.

2. Purpose of group

A large proportion of the ILAE is made up of Junior Members. Involving this Next Generation of epilepsy professionals/students in shaping the face of modern epilepsy care/research is one of the ILAE's foremost goals.

The aim of YES is to promote the involvement of young people in epilepsy care/research using a grassroots-style approach. This complements the activities already organised and offered by the ILAE. We involve a worldwide network of young people and promote equal representation of all regions.

A grassroots-style approach may prove effective and efficient to involve young people in organising activities that they are most interested in and to promote the active participation of young people in the epilepsy community.

2.1 Primary aim:

- To promote the involvement of young people from all nations in epilepsy care/research and the International League Against Epilepsy.

2.2 Secondary aims:

- Attract young people to epilepsy care/research.
- Establish regional networks of young people involved in epilepsy care/research with a global reach.
- Increase the number of Junior Members of the ILAE and provide incentives for Junior ILAE membership.
- Encourage the participation of young people in ILAE conferences.
- Promote the education of young people in epilepsy care/research.
- Promote training and funding opportunities to advance the careers of young epilepsy professionals both in epilepsy research and clinical care
- Create a network of epilepsy advocates both in epilepsy research and care
- Develop a worldwide network of young epilepsy professionals and promote equal representation of all regions.
- Improve networking and communication of young epilepsy professionals.
- Facilitate the involvement of young people in ILAE committees and task forces.

3. Organizational structure

3.1 Organization type:

- Section of the ILAE.

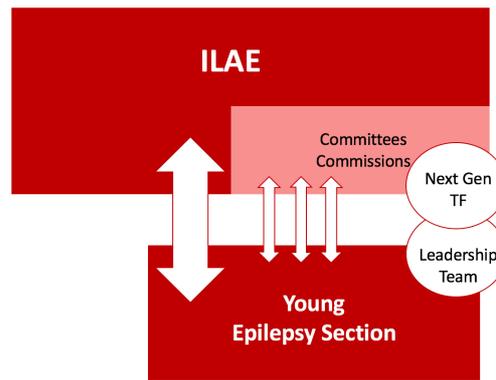


Fig. 1: Interaction between YES and ILAE.

3.2 Eligibility for Regular Membership:

- Regular Members of YES:
 - all Junior Members (age < 40) of the ILAE qualify as regular members of YES.

3.3 Annual dues:

- All YES regular members are also members of the ILAE (in chapters where this is available) and the ILAE does collect yearly membership dues. YES does not collect any additional dues.

3.4 Rights of Regular Members

- Each member is eligible to vote in elections at the biennial meeting of the general assembly or to appoint by writing one voting representative to cast the member's vote.

3.5 Non-voting membership

The YES Leadership Team has the authority to establish and define non-voting categories of membership. We offer affiliate membership to non-members of ILAE aged below 40. They will be encouraged to become members of ILAE in order to participate in YES activities and to become YES regular members.

We also offer affiliate non-voting membership to contributors above 40. People above 40 at the beginning of a tenure cannot take on formally elected positions on the YES Leadership Team, except in situations when there is no candidate below 40 with explicit approval of the YES board.

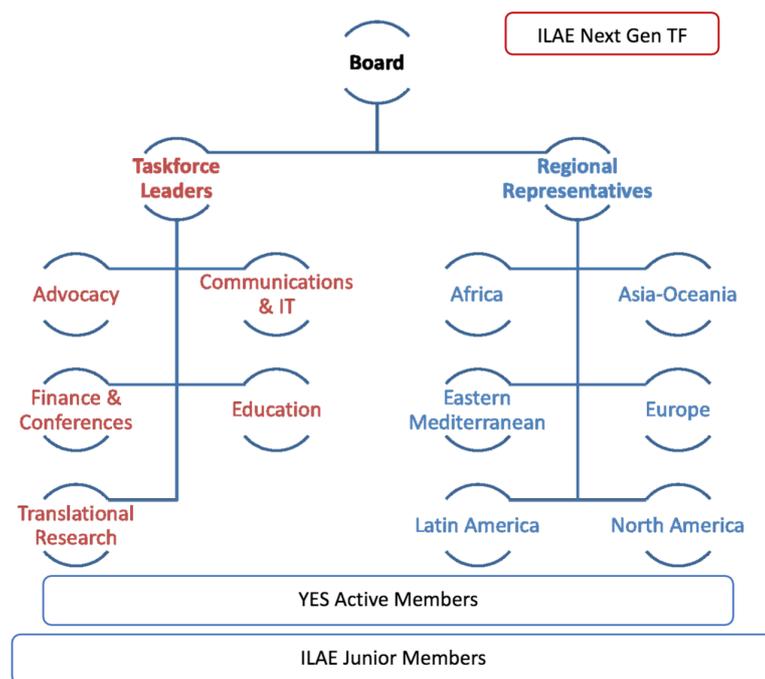


Fig. 2: Example organisational structure of YES (as of April 2019, new task forces added June 2019)

3.6 Leadership Team

YES is presided by a Leadership Team, consisting of a board, regional representatives, and task force leaders. The structure of the Leadership Team is determined at the YES biennial general assembly meeting. Members of the Leadership Team are elected at a YES general assembly meeting by simple majority. Their tenure is envisaged to last two years only to promote a high turnover rate with high efficiency, but can be extended for one additional two-year tenure by re-election at a YES general assembly meeting. They shall, upon election, immediately enter upon the performance of their duties and shall continue in office until their successors shall be duly elected and qualified.

Requirements for elected members of the YES Leadership Team are:

- Member of an ILAE chapter.
- Age < 40 when beginning the tenure.

In exceptional situations, when a candidate meeting the above criteria cannot be found (e.g. age above 40), the leadership position can be taken on by a person not meeting the above criteria with explicit approval of the YES board.

3.7 Board

The leadership team is presided by a board. The tasks and responsibilities of board members are outlined below.

Board overall:

- Conduct monthly board meetings
- Approve budget
- Approve funding requests
- Manage and approve ILAE and external committee nominations
- Approve strategic plan
- Approve internal guidelines, position documents etc.
- Regular meetings with ILAE president

Chair:

- Chair Leadership Team meetings
- Chair Board meetings
- Draft strategic plan
- Chair and organise YES general assembly meeting
- Responsible for organising International Epilepsy Congress or delegate responsibility
- Communicate with ILAE executive

Vice-Chair:

- Support chair with above tasks
- Take over responsibility in absence of Chair
- Additionally, lead a task force in area of expertise

Secretary:

- Support chair with internal/external communication
- Responsible for yes@ilae.org
- Draft internal documents
- Manage internal meetings, manage meeting minutes
- Manage YES newsletter
- Approve external communication (together with Communications TF lead)

Treasurer:

- Draft budget proposal
- Manage finances, communicate with Deb Flowers
- Manage and prepare reimbursement and grant applications for board approval
- Communicate with sponsors
- Communicate with YES members regarding financial matters

3.8 Regional representatives

YES has 6 regional representatives, according to the regions defined by the ILAE:

- Africa
- Asia and Oceania
- Eastern Mediterranean
- Europe
- Latin America
- North America

YES regional representatives are elected by simple majority either at the regional ILAE epilepsy congress or at the International Epilepsy Congress. The responsibilities and tasks of YES regional representatives are:

- Organise regional ILAE congress or delegate responsibility
- Communicate with regional ILAE commission
- Enhance YES diversity, recruit new YES members from region
- Organise regional activities
- Manage a small core team of regional collaborators
- Organise and chair regional YES general assembly meetings
- Nominate and actively manage national liaisons

3.9 Task Force Leaders

YES projects are organised into Task Forces, led by Task Force Leaders. The number and description of Task Forces and their Leaders are determined at the YES general assembly meeting by a simple majority.

Task Forces and their Leaders can be reviewed during the regular tenure at a YES Leadership Team telephone conference by a 2/3 majority.

3.10 Election of YES representatives for ILAE or external committees

From time to time, YES is approached to nominate representatives for ILAE or external committees.

For these nominations we will follow the procedure outlined below:

1. YES member with relevant skills/expertise is nominated by the YES Board to oversee the process.
2. This nomination leader creates a position description.
3. This nomination leader circulates expressions of interest amongst YES members. In the interests of YES putting forward the best possible junior candidate, the leader also has leeway to directly approach junior members they feel would be high calibre candidates to apply. These targeted applicants would be strongly encouraged to become active members of YES as well so that the views of YES are represented at this ILAE level.
4. The nomination leader assesses all applications. Guidance regarding the expertise of specific applications can be sought from other YES Leadership team members e.g., Regional Reps
5. The nomination leader prepares a ranking of the applicants based on their qualification for the role and submits the proposed ranking to the YES Board for approval with clear rationale as to their decision. The YES Board confirms/selects the nominee based on this ranking. This final step is included to avoid any suggestion of nepotism or favouritism by the nomination leader.

3.11 National liaisons

A YES National Liaison is a representative of YES to that country¹ for a two year term, whose main task is to facilitate bilateral communication between the global YES organisation and their national chapter or similar organisation, and to disseminate information about YES and our activities that might be of interest to their peers in that country.

The YES Regional Representative co-ordinates the nomination or election of National Liaisons. The Regional Representative can choose to hold formally minuted nominations and elections at their relevant biennial ILAE regional congress (recommended), or oversee the nomination of National Representatives at the relevant national chapter meeting. To establish a YES presence in a particular country, a Regional Representative may also choose to invite an appropriate person to serve as Acting National Liaison until formal nominations can be held.

National Liaison are welcome to assemble a small, informal group of peers to help with the role although these "helpers" will not be officially recognised as YES National Liaisons themselves. The roles of the National Liaisons include, but are not limited to:

- Facilitate bilateral communication between the global YES organization and that national chapter or similar organization.
- Promoting YES and our activities on a national level at scientific meetings, courses, and via local epilepsy-related institutions.
 - This includes encouraging local junior ILAE members to become active YES members.
- Collaborating with existing national “Young Neurologists/Epileptologists/Psychologists/Basic Scientists” or similar to promote the mission and activities of YES, and to help more widely disseminate YES’ and the ILAE’s educational courses, conferences, bursaries, etc.

¹ . In some cases, rather than representing a single country, global regions might consider first establishing sub-regional Liaisons. For instance, rather than having 54 National Liaisons in Africa, in the first instance it might make more sense to have a Liaison for (e.g.,) West Africa that represents the 16 nations in this region.

- Efforts should be made to collaborate with both basic science and clinical organisations, regardless of the personal background of the National Liaison
- Partake in regional teleconferences at least twice per year, as convened and chaired by the YES Regional Representative. In these teleconferences, the National Liaison will share news, opportunities, and activities relevant to YES occurring in their country, and discuss roles for the National Liaison that are in line with YES' goals and activities for that region and globally.
- Actively contribute to the tasks and activities organised by the Regional Representative where relevant.

The National Liaison reports directly to their Regional Representative on all matters, and can only use YES branding (e.g., logos) with explicit approval of the YES Secretary (yes@ilae.org).

3.12 National chapters

The formal establishment of a national YES chapter may be suitable if a national organisation of young epilepsy professionals/students is not yet available. However, this undertaking requires a clear plan, high level of personal involvement and expertise from active YES members, a sizeable national team, and support from the national ILAE chapter. Countries with a strong rationale for establishing a national chapter of YES are advised to first speak to their Regional Representative, who can then make a case for this to the YES Board. Suitable countries approved by the YES Board will then be provided with a specialised kit for the task of establishing a national chapter, although of note, ratification of the national chapter is not guaranteed unless the formal case submitted to the YES Leadership Team is suitably robust and sophisticated.

In order for a YES national chapter to be formally recognised by YES and to gain approval for the use of the YES name, logo and branding, the following requirements must be met:

- Gain formal approval by a ILAE national chapter.
- Provide a written letter of support from a national ILAE chapter representative.
- Provide a short summary (max 2 A4 pages) of the internal structure, members, goals and planned schedules for the work of the YES national chapter.

The YES Board will review these documents and provide formal approval.

3.13 Regional and global representation of YES

YES strives to promote equal representation and to equally involve people from all continents and regions, as well as all sections of the ILAE:

- We regularly nominate regional representatives as members of the YES Leadership Team.
- We encourage equal representation of all regions within YES and the YES Leadership Team.
- We actively approach young epilepsy professionals from underrepresented regions and invite them to participate within YES.
- In the mid/long-term, we will set-up regional YES subgroups that will support activities within their region, i.e. YES national liaisons and YES national chapters.
- The group will be open to and actively promote membership from all sections of the ILAE

3.14 Interaction with ILAE Next Generation Task Force

At least 3 members of the YES Core Group should be members of the ILAE Next Generation Task Force. The nominees for this task force shall be set at the YES biennial meeting.

4. Working methods

4.1 Meetings

Biennial meeting:

- There will be one meeting of the YES general assembly every two years, held in the context of the International Epilepsy Conference.
- This biennial meeting will be organised and chaired by the YES Board.
- Agenda:
 - The agenda will be generated by a task force of the YES Core Group. A typical agenda shall include:
 - Report on activities of the previous year
 - Nomination and election of the YES leadership team.
 - Allocation of YES Task Forces
 - Timeline and schedule for the upcoming year
- Elections by simple majority. Changes to terms of reference by 2/3 majority.

Minor meetings:

- Several minor meetings of the YES Leadership Team can be held each year at large epilepsy conferences.

4.2 Communication internal

Instrumental for internal communication of the YES Leadership Team will be the biennial meeting and minor meetings at conferences. Between these meetings, internal communication will be done using an online system (e.g. Slack).

Regular telephone conferences of the YES leadership team are being held at least once per month.

4.3 Communication external

External communication will be supported by a YES Communications Task Force in close cooperation with the ILAE Communications & Social Media Task Force. It will be instrumental to inform young epilepsy professionals/students about YES activities, becoming an active YES member, opportunities for networking, etc. The main pillars of external communication will involve

- Website: part of the main ILAE website, (ilae.org/yes).
- Email address: YES operates an email address (yes@ilae.org) within ILAE to facilitate communication with ILAE Junior Members.
- Social media: YES shall be represented in social media, including Facebook and Twitter.

5. Impact and Reporting

5.1 Impact

We will measure the impact of YES biennially using hard and soft metrics. Every YES Task Force will be encouraged to define objectives and target criteria at the biennial meeting.

5.2 Reporting

- All YES Task Forces will formally report on progress during the YES biennial meeting.
- The YES Core Group Board will generate a biennial written report to the ILAE Next Generation Task Force outlining the goals, tasks, achievements, and budget of the previous year.
- YES-Members of the ILAE Next Generation Task Forces will regularly formally report to other TF-members regarding YES activities.

6. Resources

6.1 Material

No material resources currently allocated. In future, there resources might be necessary regarding the representation of YES at conferences. This might include materials for an exhibition stand, posters, banners etc.

6.2 Financial

An annual budget will be submitted as per ILAE policy through the ILAE Next Generation Task Force. The internal YES budget is managed by the YES Treasurer, who generates forms and documents for reimbursement and travel funding. The typical procedure for reimbursement of funds consists of:

- Fill in YES reimbursement form in a timely manner and send to YES Treasurer.
- YES Treasurer reviews and manages requests and prepares them for YES Board approval.
- Approval by YES Board is given at a teleconference meeting.
- YES Treasurer informs the applicant and the ILAE (Donna Cunard) about the outcome.
- The applicant provides the final reimbursement form with all receipts to Deb Flowers and the YES treasurer.