

ILAE Young Epilepsy Section

TERMS OF REFERENCE

Summary

The primary aim of the Young Epilepsy Section (YES) is to promote the involvement of young people from all disciplines involved in epileptology and from all over the world using a bottom-up approach. All ILAE Junior Members (age < 40 or still in training) qualify as regular YES members and they will be encouraged to actively support activities for young epileptologists and to take on tasks within the YES Core Group.

The YES Core Group shall be presided by a board which shall be elected at the YES biennial meeting (held in the context and vicinity of a large international epilepsy conference). At least 3 members of the YES Core Group shall be members of the ILAE Next Generation Task Force. A biennial meeting will take place in the context of the International Epilepsy Conference and is intended to structure the Core Group, to align the aims, task forces and timelines, and to stage the meeting of the YES general assembly.

External communication will be supported by YES in close cooperation with the ILAE Communications & Social Media Task Force. The impact of YES will be measured biennially using hard and soft metrics. All YES Task Forces 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, *epileptology* is defined as any aspect of clinical care or research in epilepsy. Consequently, *epileptologists* are all people involved in any aspect of epilepsy research or care in people with epilepsy. It shall be emphasised that this includes all involved disciplines – i.e. not only 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 epileptologists in shaping the face of modern epileptology is one of the ILAE's foremost goals.

The aim of YES will be to promote the involvement of young people in epileptology using a bottom-up approach. This will complement the activities already organised and offered by the ILAE. We will intend to involve a worldwide network of young people and promote equal representation of all regions.

A bottom-up strategy 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 epileptology and the International League Against Epilepsy.

2.2 Secondary aims:

These are draft aims and the detailed set of aims shall be defined at a meeting of the YES Core Group after this has been established.

- Attract young people to epileptology.
- Establish regional networks of young people involved in epileptology 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 epileptology.
- Develop a worldwide network of young epileptologists and promote equal representation of all regions.
- Improve networking and communication of young epileptologists.
- Facilitate the involvement of young people in ILAE committees and task forces.

3. Organizational structure

3.1 Organization type:

- Section of the 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 shall not collect any additional dues.

3.4 Rights of Regular Members

- Each member shall be eligible to appoint one voting representative to cast the member's vote in elections at the biennial meeting of the general assembly.

3.5 Non-voting membership

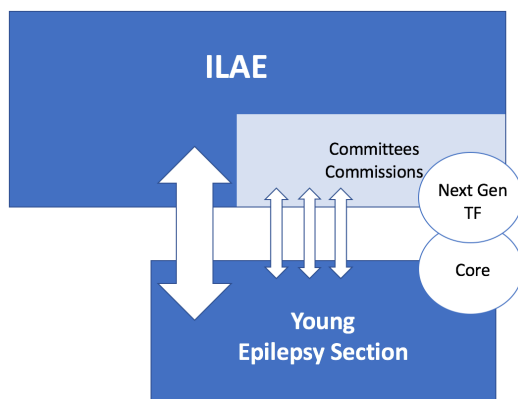
The YES Core Group shall have the authority to establish and define non-voting categories of membership. It is envisioned to offer affiliate membership to non-members of ILAE aged below 40. They will be encouraged to become members of ILAE in order to participate in YES Core Group activities and to become YES regular members.

3.6 Core Group

YES Members are further divided into active and passive members.

- Active members are those who support the activities of YES and take on tasks within the ILAE Core Group. All regular and affiliated YES members are encouraged to become active members.
- Passive members are all other members of YES.

The YES Core Group is the organisational group of all active YES members. No formal procedure is necessary to participate in the YES Core Group. All YES Members (regular or affiliated) are encouraged to actively support YES and to participate in activities of the Core Group.



3.7 Core Group Board

The YES Core Group shall be presided by a board. The number of board representatives shall be fixed from time-to-time at the YES biennial meeting but shall consist of no less than five:

- Chair
- Vice-Chair clinical
- Vice-Chair research
- Secretary
- Treasurer
- Regional representatives
 - Africa
 - Asia and Oceania
 - Eastern Mediterranean
 - Europe
 - Latin America
 - North America

Members of the board shall be elected at the YES biennial meeting by a simple majority of the regular YES members present and voting. The members of the board 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.

The YES will encourage a high turnover rate of the YES Core Group Board to promote active participation and new ideas.

3.8 Regional and global representation of YES

The YES Core Group will strive to promote equal representation and to equally involve people from all continents and regions, as well as all sections of the ILAE:

- We will nominate regional representatives as members of the YES Core Group.

- We will encourage equal representation of all regions within the YES Core Group, YES Core Group Board, and YES Task Forces.
- We will actively approach young epileptologists from underrepresented regions and invite them to participate within the YES Core Group.
- In the mid/long-term, we will set-up regional YES subgroups that will support activities within their region.
- The group will be open to and actively promote membership from all sections of the ILAE

3.9 Interaction with ILAE Next Generation Task Force

At least 3 members of the YES Core Group shall be members of the ILAE Next Generation Task Force. YES will additionally nominate at least one representative per region (see above) to the ILAE Next Generation Task Force. The nominees for this task force shall be set at the YES biennial meeting. See also section 6.2 *Reporting*.

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 Core Group 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
 - Impact of previous activities
 - Goals for upcoming activities
 - Short-term goals
 - Mid-term goals
 - Long-term goals
 - Allocation of YES Task Forces
 - Timeline and schedule for the upcoming year
 - Meeting of the YES general assembly

Minor meetings:

- Several minor meetings of the YES Core Group will be held each year at large international epilepsy conferences.

4.2 Communication internal

Instrumental for internal communication of the YES Core Group will be the biennial meeting and minor meetings at conferences. Between these meetings, internal communication will be done using an internal mailing-list (i.e. google groups). This will include space for data sharing on the cloud. Task forces will receive their own groups to facilitate discussion.

In the mid/long-term we will set-up regional YES subgroups (see 3.8). We will encourage internal communication of these subgroups and promote the organisation of regional activities.

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 epileptologists 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/young*) with a well visible tab in the top row of all ILAE sites.
- Email address: YES shall receive 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, Twitter, and Instagram.

5. Impact and Reporting

5.1 Impact

We will measure the impact of YES biennially using hard and soft metrics (see appendix A1). 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 Next Generation Task Force.

Appendix

A1 Reporting metrics

Hard metrics:

- Number of ILAE Junior Members, number of annual membership applications
- Number of Young Epileptologists (ILAE Members and Non-Members) participating in conferences
- Number of Posters / Platform presentations of Young Epileptologists at conferences
- Results of surveys after conferences.
- Visitor statistics of YES Website, external correspondance on YES email.
- Number of active YES members in Core Group. Number of YES task forces.
- Number of YES representatives per region. Proportion of regional representation in the YES Core Group and YES Task Forces.
- Number of ILAE Junior Members involved in ILAE Task-Forces

Soft metrics:

- Achieving the target criteria in YES Task Forces.
- Achieving short- and mid-term goals as defined at YES biennial meeting.
- Establishing specific program items for young epileptologists at conferences.
- Representation of YES at conferences (i.e. exhibition stall).

5. Implementation / Schedule

A2 Goals

Short-term (10/2017 – 06/2018):

- Identify collaborators for core group
- Organisational structure of Young Epileptologists core group
 - Prepare and organize Kick-off workshop
 - Identify goals
 - Identify tasks
 - Set up workgroups and task forces
- Survey among young epileptologists

Mid-term (07/2018 – 12/2019):

- Set up working Young Epileptologists group within 1 year (e.g. Vienna 2018)
- Actively approach young epileptologists in underrepresented regions, promote equal representation within the YE Core Group
- Communication / Visibility (website, mailinglist, facebook etc.)
- Increase involvement of young epileptologists in ILAE conferences
 - Forum proposals at conferences
 - Exhibition stand of YE at conferences
 - YE Symposium at IEC
 - Mentoring, Leadership program
- Involvement in specific ILAE task forces (e.g. Next Generation, Education, Communication)

Long-term (12/2019 onwards):

- Incentives for ILAE membership
 - Promote early ILAE membership in young epileptologists
- Attract young people for epileptology
 - Offer education events & activities for students, trainees etc.

- Improve communication between young epileptologists to attract a broader group of young people.
- Equal representation of all regions within the YE Core Group
- Create regional YE subgroups and promote regional YE activities
- Increase participation in ILAE conferences
- Improve networking & communication (clinical / research)
- Facilitate involvement in ILAE committees

The above goals are a draft proposal. A detailed list will be generated at the kick-off workshop in the first quarter of 2018.

5.2 Schedule

The organisational structure of YE shall be established during the first half of 2018. An aim is to establish the first YE activities at the 2018 European Conference on Epileptology in Vienna. Below is a suggestion for a schedule for the upcoming months:

End of September 2017:

- Two forum proposal were submitted for ECE Vienna 2018.
- Young epileptologists were approached through email and social media to identify potential active collaborators for YE core group.

October:

- Define YE Terms of Reference
- Set-up mailing-list for YE Core Group
- Define organisational form of YE within the ILAE

October/November:

- Formulate budget of the ILAE Next Generation Task Force and consider including funding for a YE workshop.
- Set up Next Gen TF meeting at AES 2018 in Washington (goal to generate agenda for in-person workshop in spring 2018).
- Suggest YE representatives for selected ILAE taskforces (i.e. Communications & Social Media TF).

December:

- YE meeting at AES in Washington, recruitment for YE core group.

First quarter 2018

- YE kick-off workshop to establish active core group, formulate YE goals, delegate tasks, nominate regional representatives for Next Generation Task Force.

Second quarter 2018

- Email survey among ILAE members regarding goals for Next Generation task force and Young Epileptologists consortium.
- Increase visibility of Next Generation and YE on ILAE website and other communication-channels and improve content on these pages.
- Approach young people from regions underrepresented within the ILAE. Nominate regional representatives.