

## Young Epilepsy Section

### 2021 Annual Report

#### **Purpose**

The Young Epilepsy Section (YES) of the ILAE is a worldwide multi-professional organisation with contributors at an early career stage (<40 years of age) and interested in epilepsy care and/or research. Since its establishment in 2018, YES aims to equitably support members in their professional development, engagement with epilepsy community and with ILAE activities. This mission creates a new generation of epilepsy experts poised to discover and deliver state-of-the-art care to people with epilepsy well into the future. In this way, we underpin the ILAE's vision of a world where no person's life is limited by epilepsy.

#### **Contributors**

The ILAE-YES has registered over 800 members globally (819 as of 10 March 2022) contributing at different levels. In regard to professional background, the group is very diverse, including trainees and professionals in clinical and basic/applied science, nurses, physicians, students, psychologists, pharmacologists, physicists, mathematicians, nutritionists, and other allied health professionals with interest in epilepsy.

#### **Governance**

The leadership team is composed of the chair, vice chair, secretary and treasurer, as well as the six regional representatives (one per each ILAE region) who are elected to represent YES members for a two-year term. The chair, vice chair, secretary and treasurer compose the YES Board. Elections for the YES Board take place at the YES General Assembly Meeting (GAM) during each International Epilepsy Congress, and members from all regions are invited to vote. The YES regional representatives are elected by YES members at a regional level during each respective regional congresses. The mismatch of terms allows for overall continuity and progress of projects. Prior congresses, YES members are openly invited to submit their intention of being part of the leadership team via formal application (curriculum and letter of intention/action plans).

The last elections for the YES Board occurred during the 34<sup>th</sup> IEC (online) on September 2021. The elected 2021 - 2023 Board is: Chair Yamile Calle-Lopez (Latin America), Vice Chair Sebastian Ortiz De La Rosa (Latin America), Secretary Pablo Casillas-Espinosa (Oceania), Treasurer Cristina R. Reschke (Europe). Exceptionally, due to the postponement of the regional congress, the European Representative was elected during the same congress and is Luca De Palma.

Regular open leadership team meetings, chaired by members of the YES Board, are central to the internal organisation, planning and action of YES. These bi-weekly meetings, hosted on Zoom platform, aim to inform about ILAE and YES activities, brainstorm about ongoing projects and new initiatives, allocate, assess and (if necessary) redistribute

tasks/responsibilities. The meetings are open to all YES members and their active participation is strongly encouraged. Active communication between meetings is kept on the Slack platform. Currently, the YES Slack platform counts with more than 10 channels and over 21,000 messages have been exchanged during the last two years. Additionally, the YES Board meets bi-weekly in order to act upon any priority and structure the work.

Noteworthy, YES representation within ILAE committees, commissions and task forces has been continuously increasing. In order to elect the YES members interested in those initiatives, YES developed a fair, inclusive, diverse and transparent procedure to allocate the possible best representatives, tailored to each available leadership position within the League. Therefore, open nomination calls are advertised on Slack for self-nomination. Applications are blindly ranked based on CV and letter of intention by the leadership Team, preserving different disciplines, regions and gender balance.

## Global and Regional Overview

ILAE-YES provides a flexible framework to establish local, regional, or international young people interested in epilepsy care and research. This effort aims to empower young people globally, increase diversity, and address issues using a grassroots-style approach.

Our global backbone is a network of regional representatives encompassing all six ILAE regions and national liaisons for most ILAE national chapters. Some regional ILAE-YES groups follow a more structured approach with their task forces and committees.

A pragmatic procedure has been established to support and formalise the creation of **ILAE-YES national chapters** that are closely affiliated with local ILAE national chapters. Some of the most active ILAE-YES national chapters have been Italy, the United Kingdom, Russia, Canada, Japan, and Finland. These chapters are working towards addressing local issues that cannot be adequately tackled at the international level. ILAE-YES national chapters have organised or co-organised several conferences specifically aimed at young people in their region.

## Webinars

A highlight of our regional efforts that reached a global audience was the creation of **ILAE-YES webinars** by ILAE-YES Latin America. Our representatives in Latin America recognised the urgent need for continued epilepsy education during the early stages of the pandemic. The webinars have envisaged a series of open-access lectures by epilepsy experts about current relevant topics of epilepsy care, which are aligned with the learning objectives of the ILAE academy curriculum. These highly successful webinars have been regularly live streamed on YouTube since May 2020 and continue to this date.

Moreover, the webinars can be accessed on demand at our YES YouTube. On 16 March 2022, the YouTube statistics showed 290,000 impressions; 17,000 views; 21,000 hours of watch time; 37.7% of viewers between 25-34 years old; 40.3% between 35-44 years old; an audience from over 40 countries; and a distribution by gender as follows: female 52.8%; male 47.2%. Also, our channel has 2,180 subscribers. Some of the most popular webinars covered

topics on genetic testing, neonatal seizures, scalp EEG interictal discharges mapping, SEEG and status epilepticus.

## Educational initiatives

- **Pocket cards:** The pocket cards project started in 2021 to design a concise review of clinical subjects of interest that can be carried around easily and consulted when in need.
- **Sharp Waves podcast:** YES social media outreach has been expanded by a collaboration with ILAE to launch a joint podcast about hot topics in epilepsy, called *Sharp Waves*. The first two streams have been available since the beginning of 2022 over different platforms such as Spotify.

## Collaborations

Since the last trimester of 2021, YES started two major collaborations on social media. The first one is with '**EEG Talk**', an academic-based Twitter, Instagram, and YouTube account in English (USA, Harvard University). The aim of this collaboration is to make EEG teaching more accessible and understandable for neurology residents, epilepsy, and clinical neurophysiology fellows around the globe. The second one is with '**Epilepsy Sparks**', an advocate-based Twitter, Instagram, and YouTube account in English (UK), which aims to bridge the gap between patients, neurologists, and scientists. The collaboration has been set with the epilepsy advocate and CEO of Epilepsy Sparks, Torie Robinson, and aims to increase the visibility of YES members from all different regions within the broader scientific and non-scientific community. Thus, through a series of interviews, YES members will have the possibility of showcasing their research/work, speak about their careers, and/or any concern/relevant topic to their region.

## Task Forces

YES responded to the challenges posed by the pandemic by increasing our online media presence. This strengthened the role of social and interactive media in the community of young epilepsy professionals. ILAE-YES members curate several Instagram and Twitter accounts and translate ILAE content into several languages. Several articles have been prepared for the Wikipedia initiative that is being prepared for publication. ILAE-YES members contributed to the launch of the ILAE Academy by designing cases and developing content for the online platform. Epilepsy advocacy efforts are being supported by developing materials and documents on epilepsy for laypeople.

Unfortunately, the pandemic disrupted most of our signature plans for 2020 and 2021. A pilot programme of visiting scholarships which was postponed in 2020, will see the light in 2022 due to a more relaxed travelling policy around Europe. Similarly, our peer-to-peer mentoring, networking events, brainstorming and career development sessions had to be adapted to be offered as interactive online activities. Our list of opportunities and courses targeting young epilepsy professionals had to be continuously updated due to a cancellation or postponement of most face-to-face courses.

## Recommendations for Future Work

YES will continue developing educational materials, providing online educational content, improving membership engagement, and strengthening local activities in the upcoming year. We will continue to build pocket cards and infographics as educational resources for young epilepsy professionals. YES will continue providing educational webinars and podcasts and extend them to research-oriented topics like journal clubs and method sessions. Moreover, an improvement to the registration of new active contributors within ILAE-YES and strengthen their active engagement will be prioritised. Lastly, YES will reorganise some of the taskforces to make them more efficient and to guarantee a rotation of YES members who can give new and exciting ideas to continue the great work done so far.

*Submitted by Drs Yamile Calle-López, Pablo Casillas-Espinosa, Cristina Reschke and Sebastian Ortiz de la Rosa on behalf of YES Leadership Team.*