

Young Epilepsy Section (YES)



Marian Galovic

Chair

Marian Galovic (UK)

Members

Christos Lisgaras (Greece), Vice-Chair
Genevieve Rayner (Australia), Secretary
Katja Kobow (Germany), Treasurer

Regional Representatives

Naluca Mwendaweli (Zambia), Africa
Mohmad Farooq Shaikh (Malaysia), Asia/Oceania
Reem Alyoubi (Saudi Arabia), Eastern Mediterranean
Caroline Neuray (Austria), Europe
Johann Sebastian Ortiz De la Rosa (Colombia), Latin America
Taylor Abel (USA), North America

Task Force Leaders

Advocacy – Manuela Ochoa-Urrea (Colombia)
Education – Christoph Schoene-Bake (Germany)
Career Development – Katja Kobow (Germany)
Research – Christos Lisgaras (Greece)
Publications – Nadia Khan (USA)
Opportunities – Victoria Gruber (Austria)
Conference – Caroline Neuray (Austria)
Visiting Fellowships – Mirja Steinbrenner (Germany)
Communication – Neha Kaul (Australia)
Interactive Media – Patricia Saletti (USA)

Aims/Goals of the Commission

At the 2019 International Epilepsy Congress (IEC) in Bangkok, the Young Epilepsy Section (YES) of the International League Against Epilepsy (ILAE; ILAE-YES) celebrated its first year of operation with chocolate cake and vision. Specifically, the milestone was a time to formally reflect on the mission and organizational structure of ILAE-YES moving forward, as well as a time to recognize our many achievements to date.

The Young Epilepsy Section (YES) of the ILAE 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 worldwide 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 allied health professionals.

Commission Activities and Accomplishments



Contributors

Within its first 18 months, ILAE-YES attracted an active group of more than 400 young people involved in epilepsy care and research the world over. Thanks to our grassroots organizational structure, our collaborators directly contribute to our task forces and regional programs via our online internal communication platform on Slack. Contributor numbers continue to climb as a result of our prominent ILAE-YES booths at the IEC and all ILAE regional congresses.

Governance

Regular Leadership Team meetings, chaired by members of the Board, are central to the internal workings of YES. These bi-weekly Zoom conferences are useful to discuss projects, allocate tasks, and distribute responsibilities. In the latter part of 2019, these meetings were opened up to all contributors to ILAE-YES, both to improve the transparency of our operation, and so that our programs and task forces may benefit from the expertise and enthusiasm of our collaborators.

At our General Assembly Meeting in Bangkok, the ILAE-YES Terms of Reference were updated and approved. In particular, the responsibilities of the Leadership Team were formalized, a transparent process for nominations of YES representatives for external (i.e., ILAE) committees and task

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forces was developed, the positions of National Liaisons were defined, and guidelines for the approval of national YES chapters were proposed. At this meeting, the Leadership Team was re-elected, and the structure of the task forces re-defined.

Activities Overview

YES received an annual budget through the ILAE Next Generation Task Force. This enabled us to efficiently and independently carry out activities throughout the year for the benefit of young people involved in epilepsy care or research. The majority of these funds flowed into projects at ILAE conferences, specifically targeting young attendees (networking and social activities, scientific brainstorming events, career development sessions) and into numerous travel bursaries to assist our most active YES contributors in attending the IEC and ILAE regional congresses.

Regional Overview

ILAE-YES regional representatives have organized meetings at all regional ILAE congresses to date, to introduce YES and its mission to their peers, and to develop organizational structures for YES in their region. To this end, many regional representatives have appointed national liaisons to YES, with an aim of appointing a liaison for each country within their region so that there is a direct link between YES and each chapter of the ILAE worldwide. There is also a handful of YES National Chapters established in countries with a particular need for a dedicated junior branch of the local ILAE chapter. The diversity of needs amongst the global ILAE regions is recognized, however, with national liaisons planned to span several small countries in Africa, or else numerous national liaisons to cover the globe's more populous countries such as China.

Reflecting the great support that ILAE-YES enjoys from the ILAE Executive Committee, our members have been appointed to the Scientific Organizing Committees of each regional congress and the Paris IEC, to ensure that the needs and expectations of junior conference participants are addressed. Two members from YES Africa have also joined the ILAE Task Force on Research Advocacy and Priorities.

Task Force Overview

To facilitate and support internal communication among ILAE-YES members, the *YES Communications Task Force* created an online sign-up sheet and mailing list linked to the YES website (www.ilae.org/yes) in accordance with international privacy protection standards, publish the regular YES newsletters, created a YES branding profile, and undertook a successful trial of creating five infographics of key ILAE position papers in collaboration with the ILAE Communications and Social Media Task Force. In conjunction with *Epileptic Disorders*, the YES Communications TF (task force) facilitated the posting of short clinical cases on social media to enrich online education opportunities.

In close collaboration, the *Interactive Media Task Force* curates our social media accounts on Facebook and Twitter in multiple languages, with content so far available in Arabic, Spanish, Japanese, German, Portuguese, and French.

The *Advocacy Task Force* works to increase YES engagement in low resource regions and has established relationships with key epilepsy advocacy associations, such as the IBE. The Advocacy TF leads YES celebrations for Purple Day and International Epilepsy Month via social media, in addition to providing resources for YES members to deploy at their local hospital or community.

The *Education and Career Development Task Forces* successfully developed a Peer2Peer (P2P) Mentoring Program, which connects experienced clinical fellows/researchers with younger early career colleagues (e.g., resident, PhD student, etc.) to act as mentors. The trial program at Bangkok saw 13 mentees selected and matched with mentors from the YES community and beyond, with encouraging feedback. This TF was also heavily involved in development of the roadmap published in *Epileptic Disorders* in 2019 as part of the ILAE Epilepsy Education Task Force's development of a competency-based curriculum for epileptology. Members from the YES Education Task Force together with senior tutors from the ILAE Education Task Force prepared modules and cases for this innovative

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curriculum. A *Visiting Fellowships TF* is currently piloting a short-term intra-regional fellowship program in Europe, with the aim of ultimately rolling it out worldwide.

ILAE-YES has continued to have a strong presence at the IEC and all the regional epilepsy congresses, thanks to efficient and fruitful knowledge-sharing facilitated by the *Conference TF* in conjunction with the YES regional representatives. This is underscored by the work of the *Research and Translation TF*, which has contributed to several conference activities such as career development forums, translational science brainstorming sessions, poster and presented prizes, and many dozen poster tours covering every topic category and led by members of the YES team. The Research and Translation TF also enjoys a productive collaboration with the *Young Neurobiologists Task Force (YNTF)* of the Neurobiology Commission, initiating joint activities on basic science and with our members invited to contribute to ILAE's Research Advocacy and Priorities Task Force. The Research and Translational TF have also joined efforts with the ILAE Wikipedia Epilepsy Initiative to collaborate on epilepsy-related entries and to this end, nine articles written by YES members have been published after review from the YES editorial team, a task now absorbed by the new Publications TF. The Research and Translational Task Force also commenced work curating a centralized database for training opportunities, courses, and fellowships; a task now taken up by a dedicated *Opportunities TF*.

Recommendations for Future Work

Despite the rapid growth of YES during its first years, there are several areas that require increased focus over the upcoming year. In particular, we will seek to increase the number and diversity of active contributors to YES; Regions particularly requiring growth are Africa, mainland Asia, and North America. To achieve this aim, we will reinforce the position of Regional Representatives, by expanding the nomination of National Liaisons targeted to these underrepresented regions, as well as the creation of National Chapters.

Much of our initial work so far has focused on improving ILAE congresses for younger participants. In the future, we aim to provide useful services throughout the year. This will involve online databases for fellowships, courses and positions, scientific tutorials, infographics, pocket cards, contributions to the education curriculum, etc. Underscoring the significant impact YES has made in its inaugural year, several ILAE committees reached out to YES to provide input and nominate representatives. We aim to expand our involvement within the ILAE to better represent the concerns of young people within the League. We have a clear target to involve YES representatives in all regional commissions, conference organizing committees, the League's Executive Committee, and several relevant task forces, and are on track to achieving this.

Report by Genevieve Rayner, Marian Galovic