

TABLE OF CONTENTS

Click a number to go to a section

President's Message



Organization & Structure



Chapter **Activities**



Strategic Plan



Intersectoral Global Action Plan



Education & Training



Congresses



Publications & Communication



Standards & Best Practice



Commissions & Task Forces



Young Epilepsy Section



Nursing **Section**



Financials



Guiding **Principles**

Click this on any page to be taken to the table of contents Contents @llaeWeb







FULL LENGTH REPORTS

If you would like to read full length reports please click on the links below!



President's & Vice President's



Education Council



Congress Council



Standards & Best Practice Council



Global Advocacy Council



Publications Council



Commissions and Sections









President's Message

As we look back over 2022, it was certainly a year of achievements, despite parts of the world still being restricted by the pandemic, and the unrest in Eastern Europe.

In May, Member States of the World Health Organization (WHO) approved the Intersectoral Global Action Plan on Epilepsy and other Neurological Disorders (IGAP), establishing a 10-year roadmap toward progress in reducing the global epilepsy treatment gap. In Geneva in July, ILAE held our first face-to-face congress in three years. Our educational platform "leveled up" to provide options for general and specialty practitioners. Cooperative webinars, e-forums, 364 commission and task force Zoom meetings, and a robust communications effort rounded out the year.

This report is a summary of our time and effort as a global team of volunteers and staff.

Thanks to all of you for your dedication.











The <u>ILAE Executive Committee</u> includes 11 elected members, as well as the executive director and chairs of each of the five councils. Elected members of the Executive Committee include the president, vice president, secretary-general, treasurer, immediate past president, and chairs of each of the six recognized ILAE regions: Africa, Asia-Oceania, Eastern Mediterranean, Europe, Latin America, and North America. Elections are held every four years.

The five councils — Congress, Global Advocacy, Education, Publication, Standards & Best Practice — provide oversight and governance in each area.

Upon taking office, the ILAE president establishes multiple commissions and task forces to carry out the work of ILAE.

ILAE has established two sections — the <u>Young Epilepsy Section</u> and the <u>Nursing Section</u> — consisting of ILAE members affiliated with specific groups.

Several committees support ILAE's finances and budgeting process, as well as manage elections.

Staff members provide support for all aspects of ILAE activities, including communications, congresses, education, and financial affairs.









Roberto Caraballo Vice President



Alla Guekht Treasurer, Chair, Global Advocacy Council





Secretary General



Sam Wiebe Past President



Ingmar Blümcke Chair, Education Council



Jean Gotman Chair, Publication Council



Nathalie Jette Chair, Standards & **Best Practice Council**



Jo Wilmshurst Chair, ILAE Africa



John Dunne Chair, ILAE Asia & Oceania



Ghaieb Aljandeel Chair, ILAE East Mediterranean



Matthew Walker Chair, ILAE Europe



Mario Vanegas Chair, ILAE Latin America



Jaideep Kapur Chair, ILAE North America



Eugen Trinka Strategic Advisor ex officio



Julie Hall **Executive Director** ex officio



J Helen Cross

President,

Chair, Congress Council



Francesca Sofia **IBE President** ex officio



Gus Baker IBE Secretary General ex officio



IBE Treasurer ex officio







ILAE Councils

Each council is aligned with one of the goals under Strategy 2030. They are "standing" (ongoing) entities responsible for long and short-term planning, policy review, and recommending a course of action to the Executive Committee.











Alla Guekht Chair



Jean Gotman Chair



Nathalie Jette Chair

Congress Council enhances the quality, relevance, and profile of ILAE congresses, steps needed to stay abreast of technical and educational advances in congresses, and financial sustainability of ILAE congresses.

Education Council devises strategies to enhance the quality, relevance and profile of ILAE educational activities, steps needed to stay abreast of technical and educational advances as well as manages the financial sustainability of ILAE education activities.

Global Advocacy Council formulates strategies to enhance the quality,

relevance, and profile of ILAE global advocacy activities, steps needed to stay abreast of needs and opportunities for global and regional advocacy initiatives, and activities.

Publication Council

recommends strategies to enhance the quality, relevance, and impact of ILAE publications. The Council stays abreast of technical and publishing innovations, monitors financial stability of publications, and guides policy.

Standards and Best Practice Council was recently created with the aim of overviewing all aspects of ILAE's work on the development, effective dissemination, and efforts at implementing clinical practice guidelines and best practice standards in epilepsy.





Linda Beza **Director of Finance**



Priscilla Shisler Director of Engagement & Education



Laurie Beninsig Managing Editor, Epilepsia® & Epilepsia Open™



ILAE Academy Consultant



Lauren Coleman Registration Officer



Gus Egan Chapter & Membership Senior Development Manager



Briana El-Naggar Registration Officer



Oliver Gubbay Managing Editor, **Epileptic Disorders**



Cecelia Hartsell Program Manager, **Congress & Events**



Kathryn Hodgson Program & Partner Senior Development Manager



Andrea Hunt Program Manager, **Congress & Events**



Alma Paéz Lynch Program Manager, **Congress & Events**



Alicia McNeely Web & Social Media Manager



Jessica Norvell Administrative Assistant, **United States**



Gwen O'Brien Administrative Officer, Ireland



Haitian Power Finance Manager



Jason Ryan Digital & Design Officer

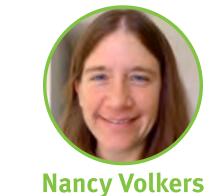


Annabelle Sellin Program Assistant





Program Manager, Congress & Events



Communications Officer









Our 128 chapters cover more than 160 countries and territories. They coordinate regular meetings and manage ongoing initiatives as well as short-term projects and educational programs, some of which involve other chapters.

Many chapters also organize and produce a national epilepsy congress each year.



Chapter activities

- Pediatric Epilepsy Training courses
- Online EEG training courses
- Online and in-person epilepsy training workshops
- School-based epilepsy awareness programs
- Symposia for clinicians (specialists and general practitioners)
- Guest spots on radio and TV programs
- Continuing medical education initiatives
- Advocacy for changing discriminatory legislation
- Educational webinars
- Participation in national standards of care in epilepsy
- Scholarships for members to attend meetings and courses

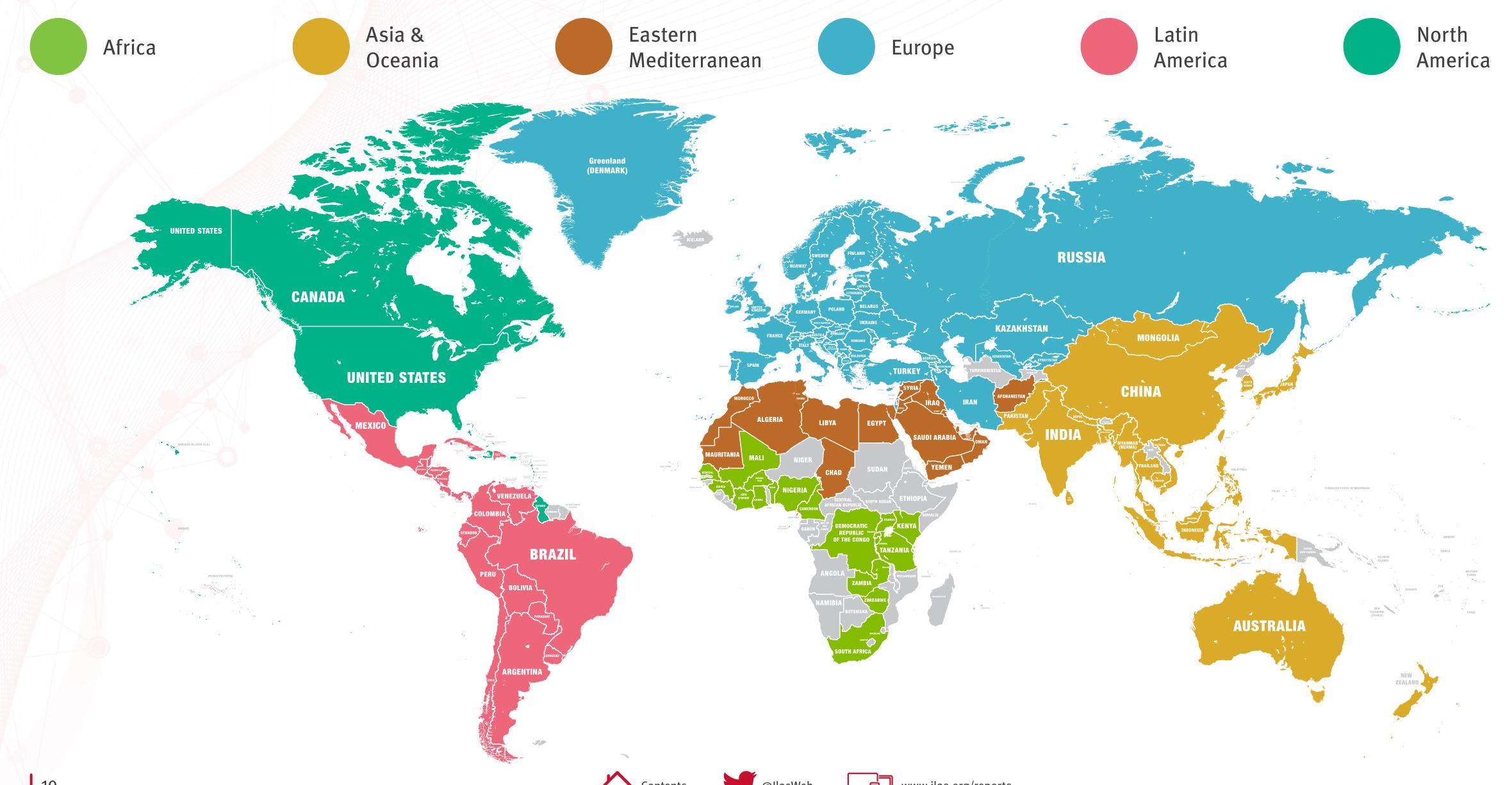
Chapter challenges

- Political uncertainty
- Erratic access to antiseizure medications
- Limited access to specialized epilepsy care and investigations
- Lack of funds
- COVID-19 restrictions























Pakistan school epilepsy awareness













Democratic Democratic Congo Republic of Congo EEG training



12











CONTRA 14 EPILEPSIA

2021 AND AGOSTO



Jordan chapter congress



Mexico national congress





























Indonesia

International Epilepsy Day







El Salvador International Epilepsy Day



Contents





Irag symposium









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Strategic Plan

ILAE's Strategic Plan will provide direction until 2030. The plan includes five goals, as well as three cross-cutting areas of support (events and congresses, communications, and publications).

Everything we do aligns with at least one of the plan's goals.









Intersectoral Global Action Plan (IGAP)

On 27 May 2022, Member States of the World Health Organization (WHO) approved the Intersectoral Global Action Plan on Epilepsy and other Neurological Disorders (IGAP) at the 75th World Health Assembly in Geneva, Switzerland. This was the culmination of many years of collaboration!

Alongside the International Bureau for Epilepsy (IBE), the International Child Neurology Association (ICNA), and the World Federation of Neurology (WFN), ILAE hosted a "What's next?" webinar addressing our collaborative work to achieve all 10 of the IGAP targets. In December, the WHO launched a technical brief that provides key information on epilepsy and recommends actions to policymakers and other stakeholders.

ILAE began planning a series of townhall meetings with chapter leaders to provide more detailed information about IGAP and to collectively develop a comprehensive implementation plan.









IGAP at a glance



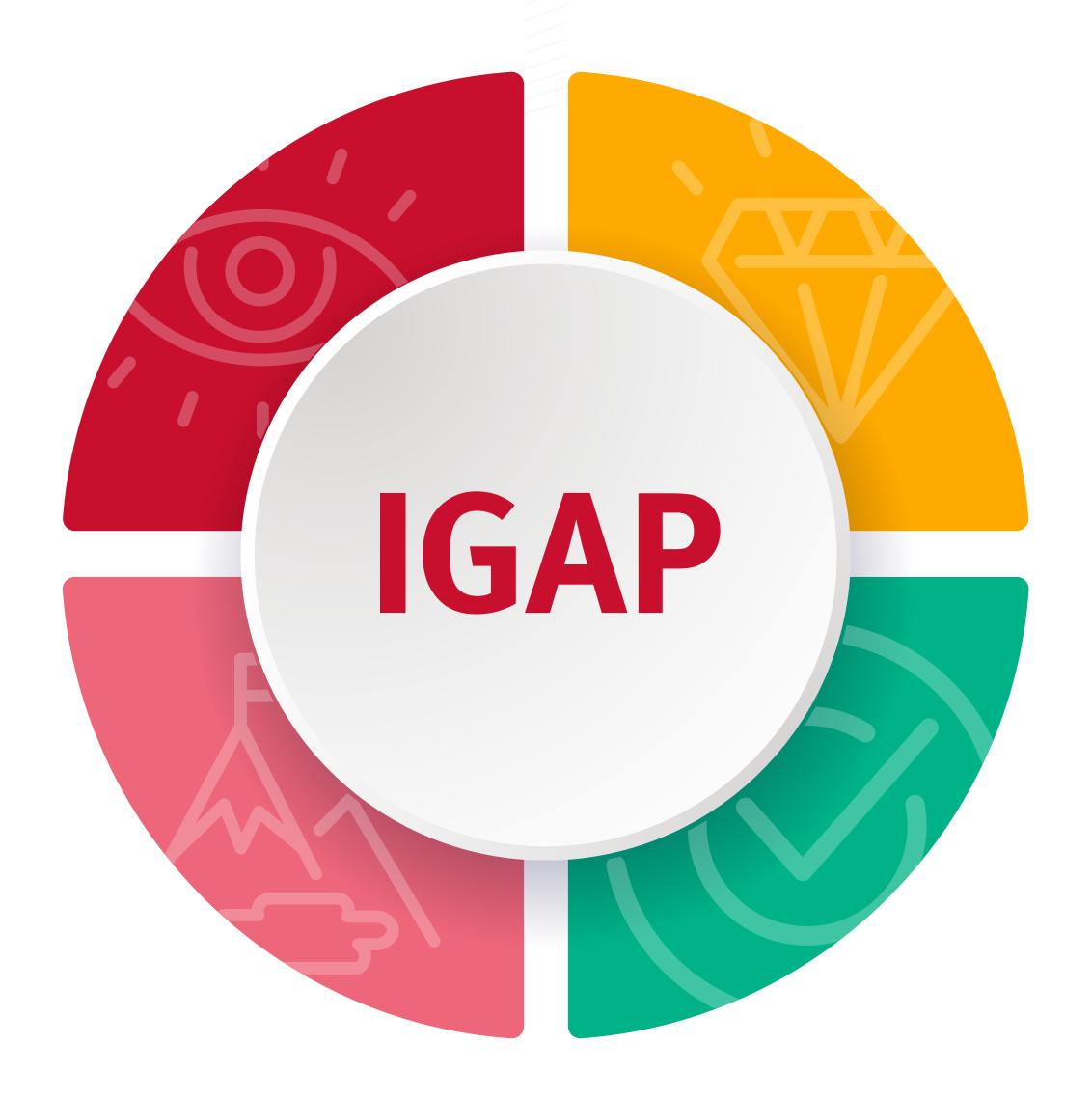
Vision

- Brain health is valued, promoted and protected across the life course
- Neurological disorders are prevented, diagnosed and treated, and premature mortality and morbidity are avoided
- People affected by neurological disorders and their carers attain the highest possible level of health with equal rights, opportunities, respect and autonomy



Goals

- To reduce the stigma, impact and burden of neurological disorders, including associated mortality, morbidity and disability
- To improve the quality of life of people with neurological disorders, their carers and families





Guiding principles

- People-centered primary health care and universal health coverage
- Integrated approach to care across the life course
- Evidence-informed policy and practice
- Intersectoral action
- Empowerment and involvement of persons with neruological disorders and their carers
- Gender, equity and human rights



Strategic objectivesTo raise the prioritization and strengthen governance

- To provide effective, timely and responsive diagnosis, treatment and care
- To implement strategies for promotion and prevention
- To foster research and innovation and strengthen information systems
- To strengthen the public health approach to epilepsy









IGAP Global Targets: What they mean for epilepsy

Closing the Treatment Gap

50% increase in epilepsy service coverage

80% of countries provide essential medicines and basic technology for epilepsy

Anti-seizure medicines UHC tracer medicines

75% of countries include
Epilepsy in Universal Health
Coverage (UHC)

Priority Benefits Package (PBP)

Closing the Inclusion Gap

80% of countries replace discriminatory laws

100% of countries have awareness campaign or advocacy program

Closing the Research Gap

100% increase in research

75% of countries have national plans, policies, strategies that include epilepsy

80% of countries routinely collect core set of epilepsy related indicators

80% of countries have an intersectoral program for brain health promotion and prevention









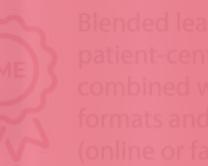
Ten-year Timeline

Phase	Year	
Phase One: Preparation and Planning	2022-2023	Preparation and plan: • Baseline survey • Regional teams to support chapter action • Strategic initiatives • Strengthening partnerships • Advocacy and awareness raising
Phase Two: Acceleration and Exploration	Mid 2023-2025	 Roll out acceleration plans for closing gaps in: Treatment Inclusion Research Exploratory work on possible epilepsy specific prevention activities and epilepsy prevention target(s)
Phase Three: Review	2025-2026	Midterm review
Phase Four: Adjust and Implement	2027–2030	Adjust and continue implementation
Phase Five: Evaluation and Prepare	2029/2030-2031	Evaluation Prepare resolution for second IGAP









Education

& Training











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Education & Training

In 2022, more than 600 professionals from 88 countries were provided access on the ILAE Academy learning platform to more than 10,000 learning sessions. The Academy Level 1 program was revised, and Level 2 was developed.





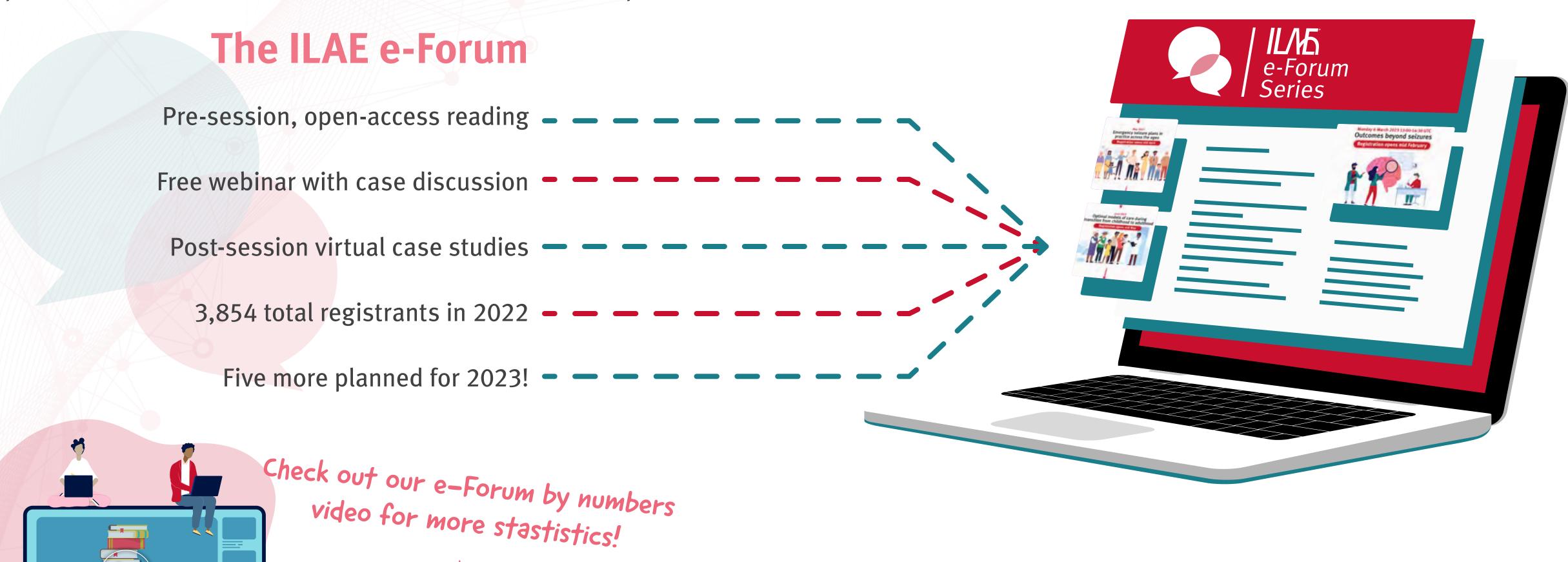
ILAE - Eastern Mediterranean and ILAE - Africa held 24 joint webinars throughout the year, 12 in English and 12 in French, attracting 3,232 attendees from all six regions.





Education & Training

ILAE launched a new offering, the e-Forum: A free webinar with pre-reading with unique open access to relevant ILAE journal articles and post-session virtual case studies. Three were held in 2022, with five planned for 2023. All e-forum sessions are recorded and posted on ILAE's YouTube channel.





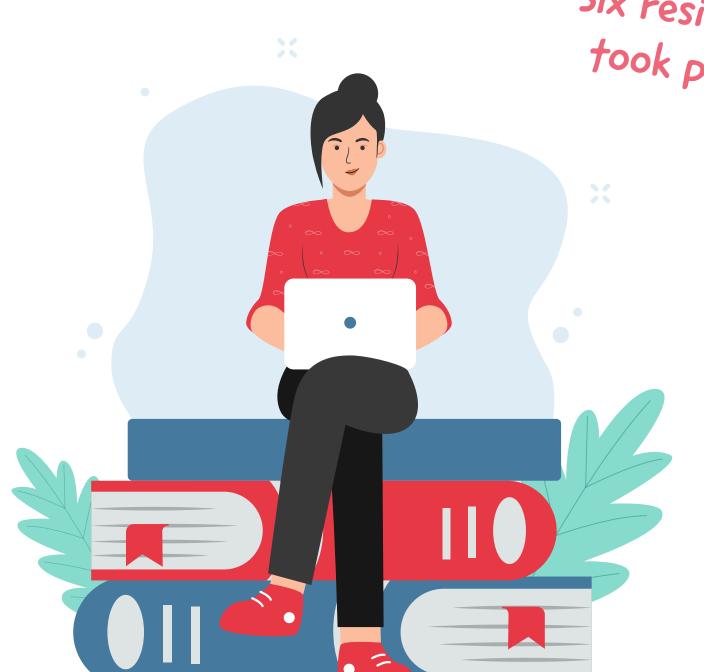


Education & Training

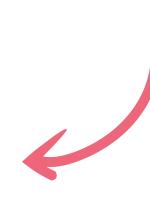
The six ILAE regions held more than 40 courses throughout the year. Courses focused on regional needs and covered topics ranging from EEGs for neonates to managing comorbidities in older people.

VIREPA courses continued in their 15th year with ILAE, including an inaugural MRI course.

ILAE continue to offer opportunities in leadership training, fellowships, visiting teacher exchanges and mentorship programs.



Six residential specialist ILAE Schools took place, open to students from around the world.





The ILAE curriculum for primary care was published as a step toward providing inclusive are for epilepsy within the primary care setting. This curriculum can be used to shape future are care epilepsy education packages. Primary health care epilepsy education packages.



Click here to check out the new primary care curriculum, available in English and Spanish!









2nd North American Epilepsy Congress

2022 | Virtual

LEARN MORE



14th European Epilepsy Congress

9-13 July 2022 | Geneva, Switzerland

#EEC2022

LEARN MORE

Consider SSES

XII Congreso Latinamericano de Epilepsia

1-4 October 2022 | Colombia

LEARN MORE &



4th Asian & Oceanian Epilepsy Congress

November 2022 | Virtual

#AOEC2022

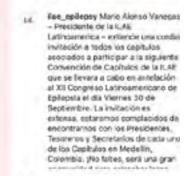
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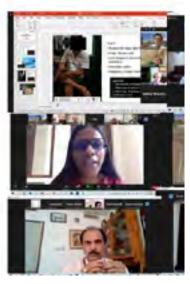


















epilepsy congress

14th European Epilepsy Congress 9-13 July 2022 | Geneva, Switzerland















/ Riyadh.





















Congresses - May



2nd North American Epilepsy Congress

5-8 May 2022 Online

138 delegates from 48 countries and 28 speakers participated in the online 2nd North American Epilepsy Congress, which for the first time focused specificially on on bridging gaps in services to small islands and remote areas.





Congresses - July



14th European Epilepsy Congress

9-13 July 2022 Geneva, Switzerland

2,062 delegates from 87 countries participated in 166 sessions with 317 speakers at the 14th European Epilepsy Congress.

Due to the pandemic, this was the first in-person ILAE congress since August 2019.



Congresses - October



XII Congreso Latinoamericano de Epilepsia

1-4 Octubre 2022 Medellín, Colombia

689 delegates participated in 46 sessions with 101 speakers at the 12th Latin American Epilepsy Congress.



46







Congresses - November



14th Asian & Oceanian **Epilepsy Congress** 17-19 November 2022

Online

515 delegates – including 171 for IBE Day – participated in 49 sessions with 140 speakers at the 14th Asian & Oceanian Epilepsy Congress.







Congresses - November





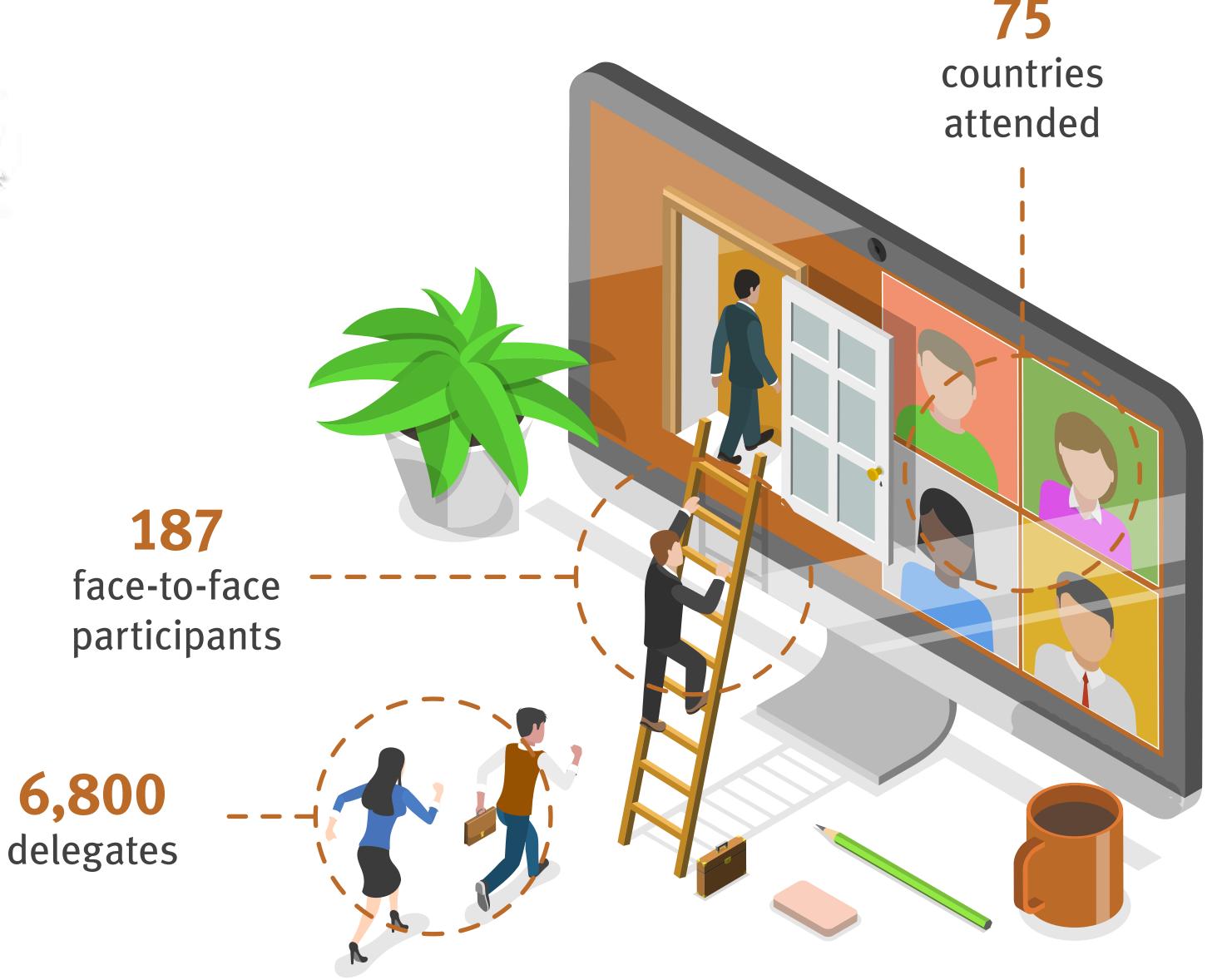


6th East Mediterranean Epilepsy Congress

16-19 November 2022 Riyadh, Saudi Arabia & Online

More than **6,800** delegates – including **187** face-to-face participants – from **75** countries attended the 6th Eastern Mediterranean Epilepsy Congress, hosted by the Saudi Epilepsy Society in Riyadh, Saudi Arabia and online.

This hybrid congress provided complimentary registration for ILAE chapter members.

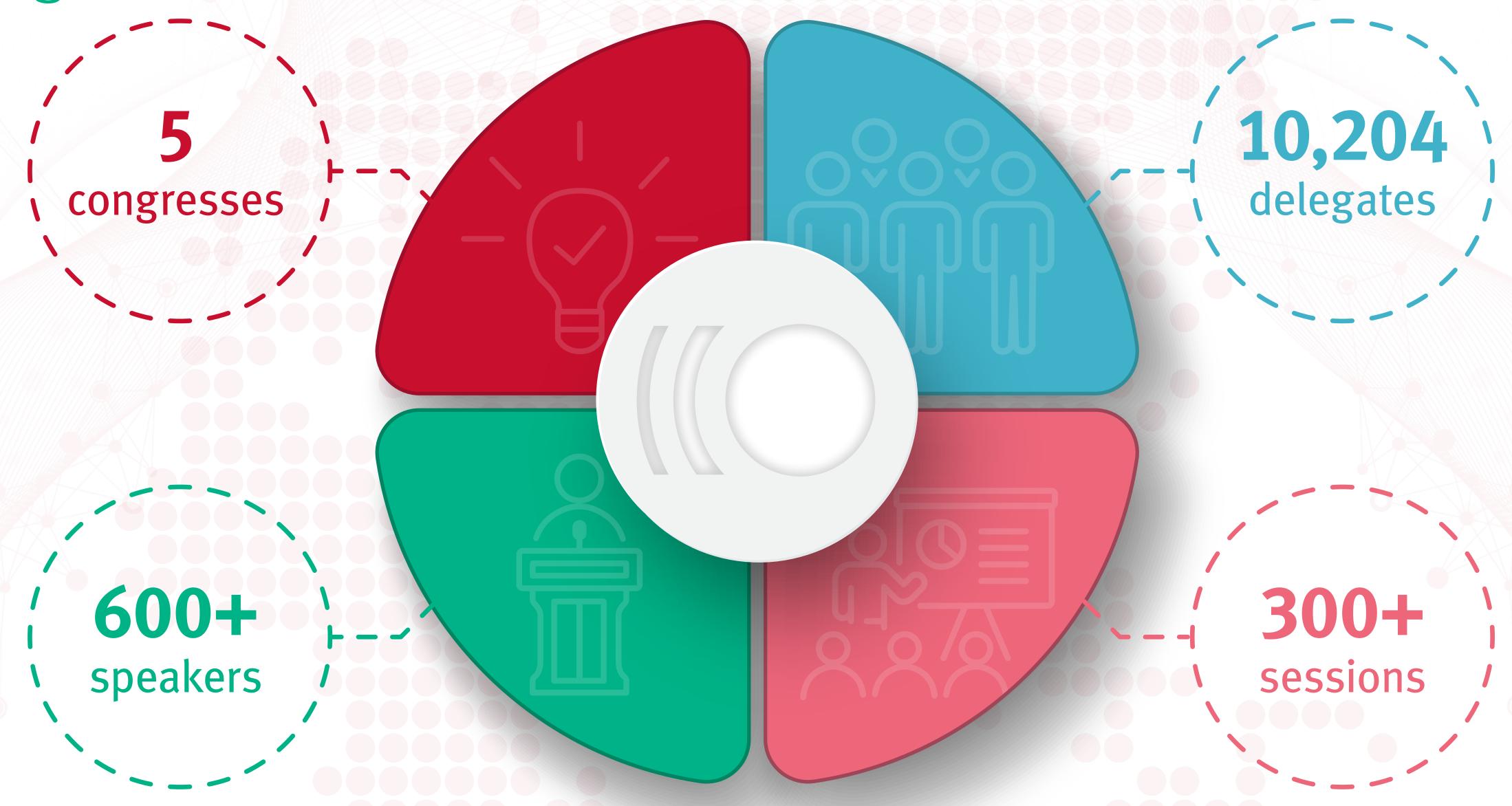








Congresses - At a Glance



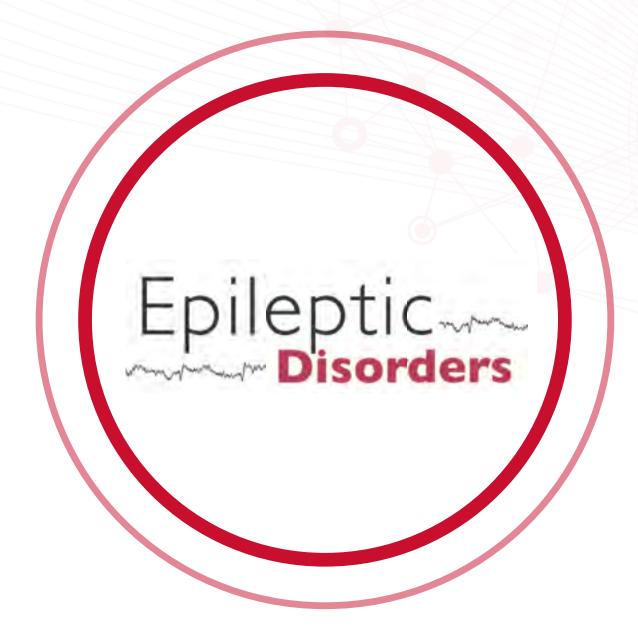


Publications & Communication

Journals









Epilepsia®

Epilepsia® achieved an Impact Factor of 6.740. It is ranked 27th of 212 journals in the clinical neurology category. Epilepsia® received 1,079 submissions in 2022 and accepted about 25% of submissions. Article downloads topped 2.4 million.

Epilepsia OpenTM

Epilepsia™ Open achieved an initial Impact Factor of 4.026. Annual submissions increased 23% over 2021; the acceptance rate is 75%. Article downloads increased nearly 50% from 2020.

Epileptic Disorders

Epileptic Disorders, our educational journal, increased its Impact Factor by 28%, to 2.333. Downloads and homepage visits doubled compared with 2021. Beginning in 2023, this journal will be published by Wiley.

Epigraph

Epigraph published 44 articles and podcast transcripts, including many French and Spanish translations. There were more than 86,000 visits to Epigraph pages on the ILAE website, a 21% increase over 2021.







Podcast



Sharp Waves

The Sharp Waves podcast released 21 episodes; it was in the top 15% of podcasts shared globally on Spotify and the top 25% most downloaded podcasts on Buzzsprout.

Website



ilae.org

Website traffic remained high, with 2.1 million visits. Guidelines and classification sections were the most visited, followed by congresses and education pages.

Wikipedia



Wikipedia Project

Thirty articles were edited in 2022. ILAE created a "Wikipedian in Residence" and established an internship program to encourage young contributors.







Social Media









YouTube

ILAE released 75 videos in 2022. There were 1,865 new subscribers, more than the previous four years combined. Total channel views reached over 65,000 for 5,220 hours of watch time.

Facebook

ILAE ended 2022 with 15,927 followers and 1,035 posts. Page reach more than doubled (114% increase) compared with 2021.

Instagram

ILAE gained more than 1,000 new Instagram followers in 2022, and page reach more than tripled (245% increase).

Twitter

ILAE had a 35% increase in followers. The 1,317 tweets earned 1.2 million impressions, a 91% increase from 2021. The Spanish Twitter account shared 201 tweets for 152,000 impressions; the French account at 156 tweets for 46,00 impressions.



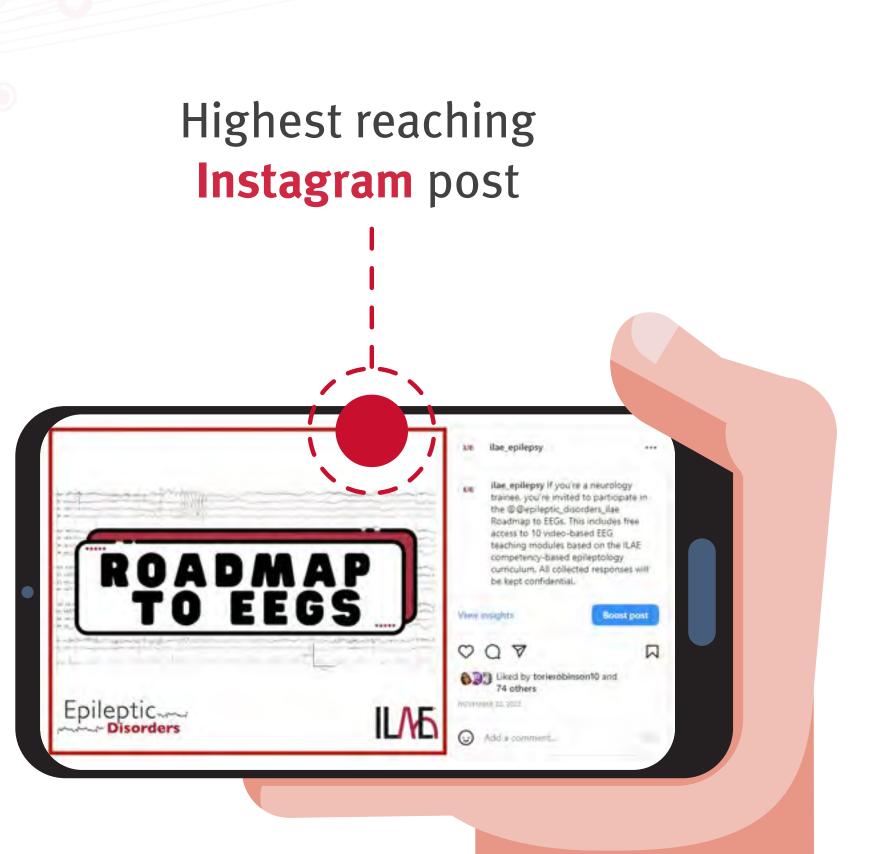




Social Media Spotlight

Highest reaching Facebook post





Highest reaching

Twitter post





Standards & Best Practice

The Standards & Best Practice Council is ILAE's newest council, established in 2021. It continues the work of the Clinical Practice Guidelines task force.

During its first full year, the council established task forces and committees and began creating an infrastructure to facilitate clinical practice guidelines. The council began the recruitment process for a methodologist, and developed a draft memorandum of understanding that will be used when developing guidelines with other organizations.

Council members approved a guideline on the minimum standards for recording routine and sleep EEG (which will be published in 2023) and provided support for several other guidelines and standards.

The council published an article in *Epilepsia*® with recommendations for developing and defining clinical practice guidelines.









Commissions & Task Forces

ILAE's 13 commissions and 61 task forces cover a wide range of topics and issues



In 2022, they held a total of 364 virtual meetings





Big Data Commission

- SNOMED Task Force
- MRI Task Force
- EEG Task Force
- Genetics Task Force

Career Development Commission

- Leadership Development Task Force
- Mentoring Task Force
- Fellowships Task Force
- Networking Task Force

Climate Change Commission

- Sustainable ILAE Task Force
- Sustainability Engagement Task Force
- Research Sustainability Task Force

Diagnostic Methods Commission

- EEG Task Force
- Neuropathology Task Force
- Neuropsychology Task Force
- Neuroimaging Task Force
- Joint ILAE-IFCN EEG Database Task Force

Epidemiology Commission

- Educational Tools Task Force
- Comorbidities Task Force
- Global Burden of Disease Task Force
- Epilepsy Definitions Task Force
- Cost of Epilepsy Task Force
- Registries Task Force

Genetics Commission

- Genetic Literacy Task Force
- Sequencing Data Sharing Task Force
- Clinical Genetic Testing in the Epilepsies Task Force
- Epilepsiome Task Force
- Consortium on Complex Epilepsies

Medical Therapies Commission

- Pregnancy & Reproductive Health Task Force
- Plant-based Medicines Task Force
- Emergency Treatments Task Force
- Dietary Therapies Task Force
- Access to Treatments/Generics Task Force
- Regulatory Affairs Task Force



Neurobiology Commission

- Training & Professional Development Task Force
- Advocacy & Dissemination Task Force
- Special Task Force on Networks
- Special Task Force on Chronobiology
- Translational Task Force
- Workshop on the Neurobiology of Epilepsy (WONOEP)

Older People Commission

- Medical Therapies Task Force
- Psychiatric Comorbidities Task Force
- Advocacy Task Force

Paediatrics Commission

- Transition to Adulthood Task Force
- Paediatric Psychiatry Task Force (cross-commission with Psychiatry)
- Neonates Task Force
- Research Advocacy Task Force
- Education (ILAE-ICNA) Task Force
- Paediatric Medical Therapies Task Force

Psychiatry Commission

- Paediatric Psychiatry Task Force (cross-commission with Paediatrics)
- Functional Seizures (PNES) Task Force
- Integrated Mental Health Care Pathways Task Force
- Psychoeducation Task Force
- Intellectual Disability Task Force

Surgical Therapies Commission

- Evidence & Outcomes Task Force
- Surgical Networks Task Force
- Epilepsy Surgery in Low-Resource Settings Task Force
- Paediatric Epilepsy Surgery Task Force
- Epilepsy Surgery Education Task Force
- Severity Scale Task Force

Terminology Commission

- Epilepsydiagnosis.org Task Force
- Status Epilepticus Terminology Task Force
- Aetiologically Driven Syndromes Task Force

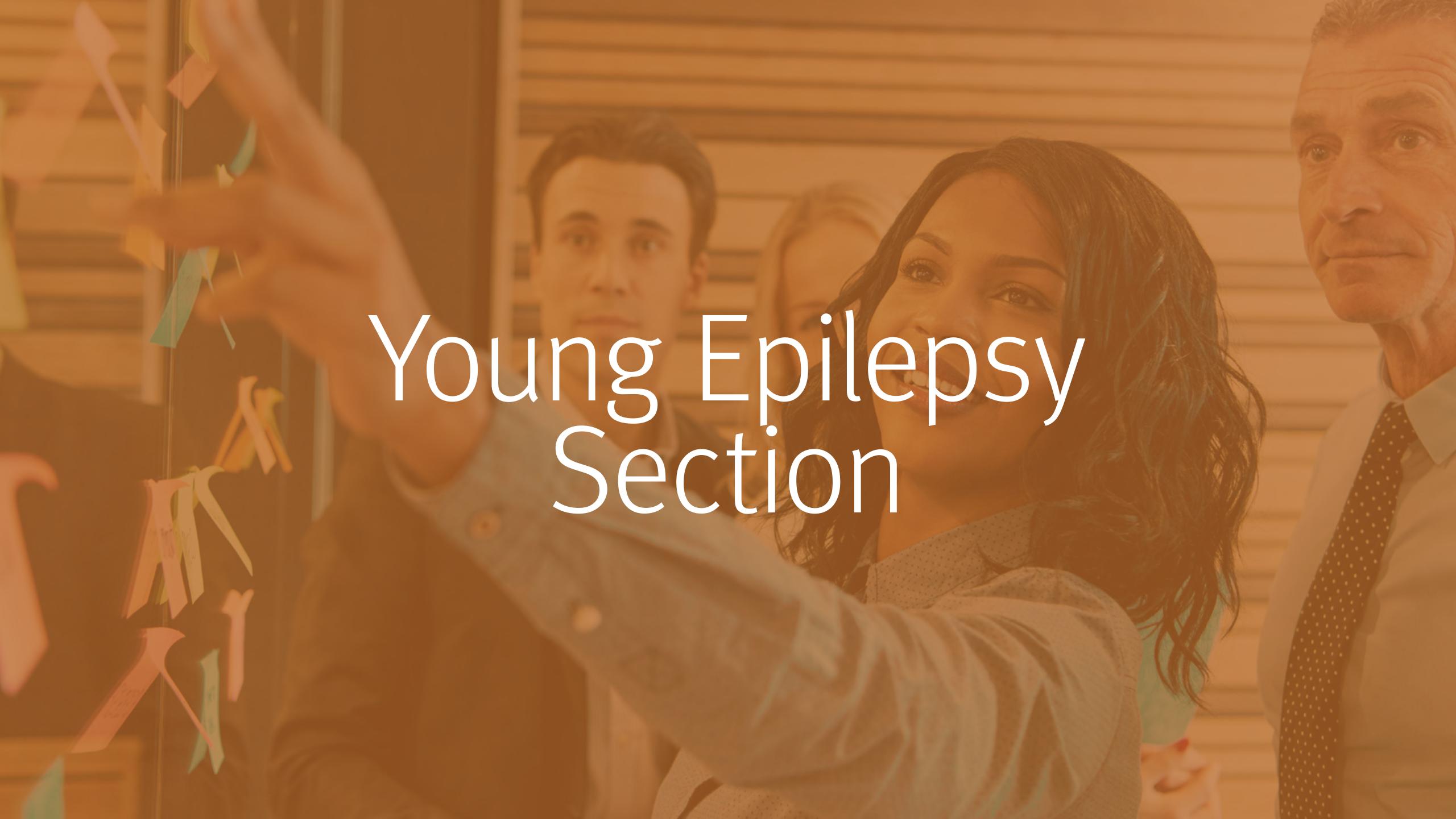
Executive Committee designated

- SUDEP Task Force
- Research and Innovation Task Force
- Telemedicine Task Force
- Epilepsy During Crises Task Force









Young Epilepsy Section

The Young Epilepsy Section (YES) added 393 members for a total of 1,685 members across all six ILAE regions.

In its fifth year, YES held networking events and educational activities at the European Epilepsy Congress, Latin American Epilepsy Congress, and Asia & Oceanian Epilepsy Congress, and a joint networking event with the American Epilepsy Society (AES) at the AES annual meeting. The group held meetings every other week from February to December. Six YES members participated as interviewers on ILAE's Sharp Waves podcast; among them, they worked on 11 episodes in 2022.

Other accomplishments include:

- Launch of the epilepsy stigma worldwide project
- Launch of the women in epilepsy project with Western University in Canada
- Creation and translation of resources for people with epilepsy during the Ukraine crisis













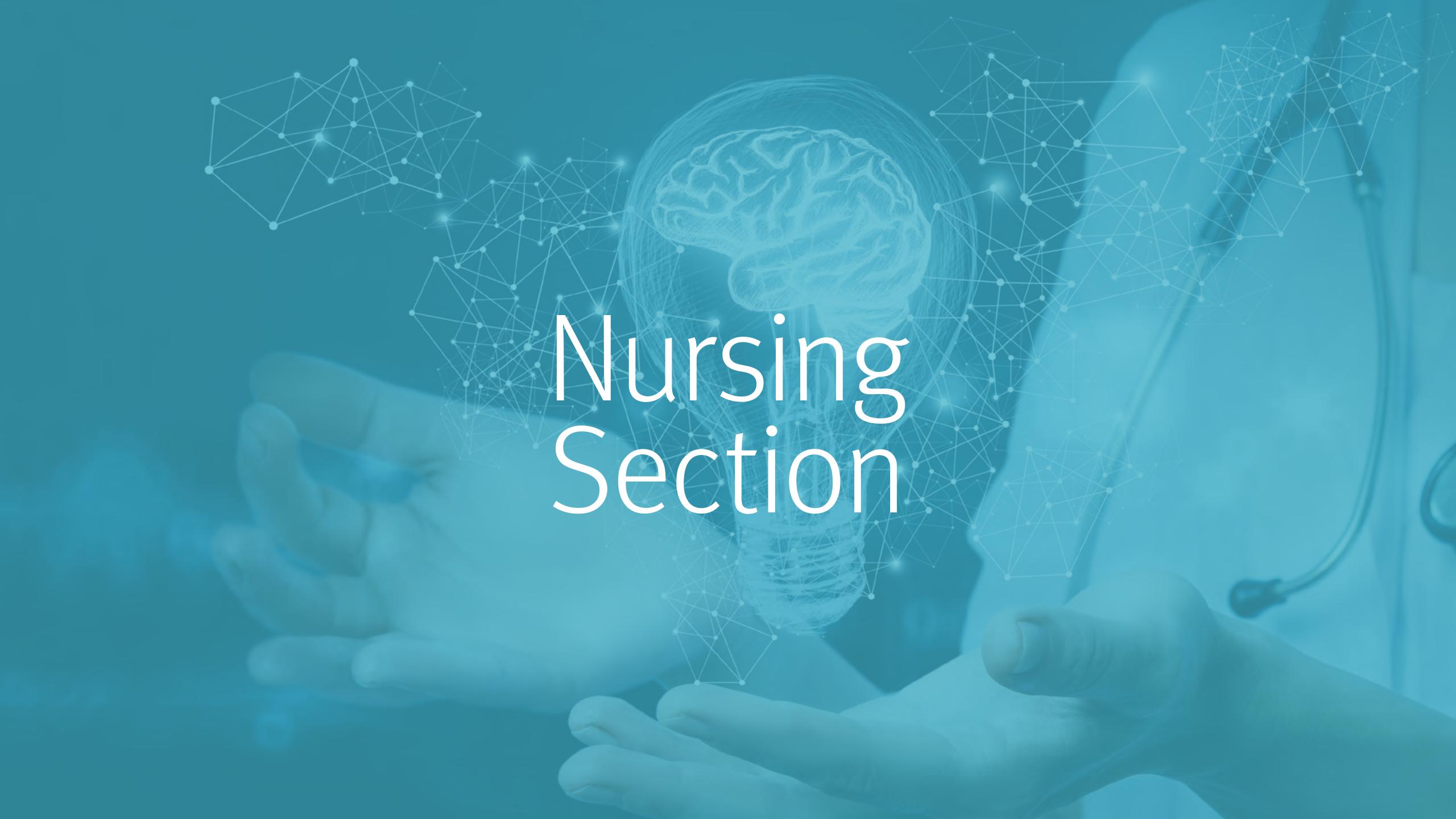












Nursing Section

In late 2021, the Epilepsy Nurse Task Force became the ILAE Nursing Section. In 2022, the section welcomed more than 550 members from 59 countries and held its first symposium by and for nurses at the 14th European Epilepsy Congress in Geneva.

The section created a needs assessment and obtained input from nurses worldwide. Three workgroups have been established, with more to come as necessary:

- Nursing education and development developing curricula for nurses in epilepsy, conducting symposia and developing written materials
- Clinical care and best practices identifying and sharing best practices, as well as quality improvement and research information
- Advocacy promoting recognition of nurses as leaders and the importance of nurses in patient-centered care

Read more about the Nursing Section in Epigraph









epilepsy

14th European Epi

9-13 July 2022



Financials - Expenses

Treasurer's Report for Financial Year 2021

Expenditures in 2021 totaled approximately US\$3.63 million, with regional activities, education, commissions, publications, and congresses accounting for 71%.

Overall expenditure throughout 2021 was reduced compared to pre-COVID years, as pandemic restrictions and travel disruptions limited the range of activities. Congresses in 2021 were delivered virtually, which impacted expected revenue. The ongoing uncertainty of the global pandemic and the need to cancel events and pivot from in-person to virtual format also had impacts on costs and staffing arrangements. Most of ILAE's global and regional education program were able to continue online; however, in-person teaching was not possible and a number of courses and summer schools could not be offered.



Other Programs	10%	Academy	12%
Congresses	26%	Publications	10%
Regions	6%	Governance	3%
Commissions	7 %	Administration	26%







Financials - Revenue

Total revenue during 2021 was approximately US\$4.62 million, with congresses and journal royalties as the two major sources.

Following the formation of ILAE Secretariat in 2020, ILAE staff continued to work on consolidating the financial activities, systems, and processes as a unified organization.

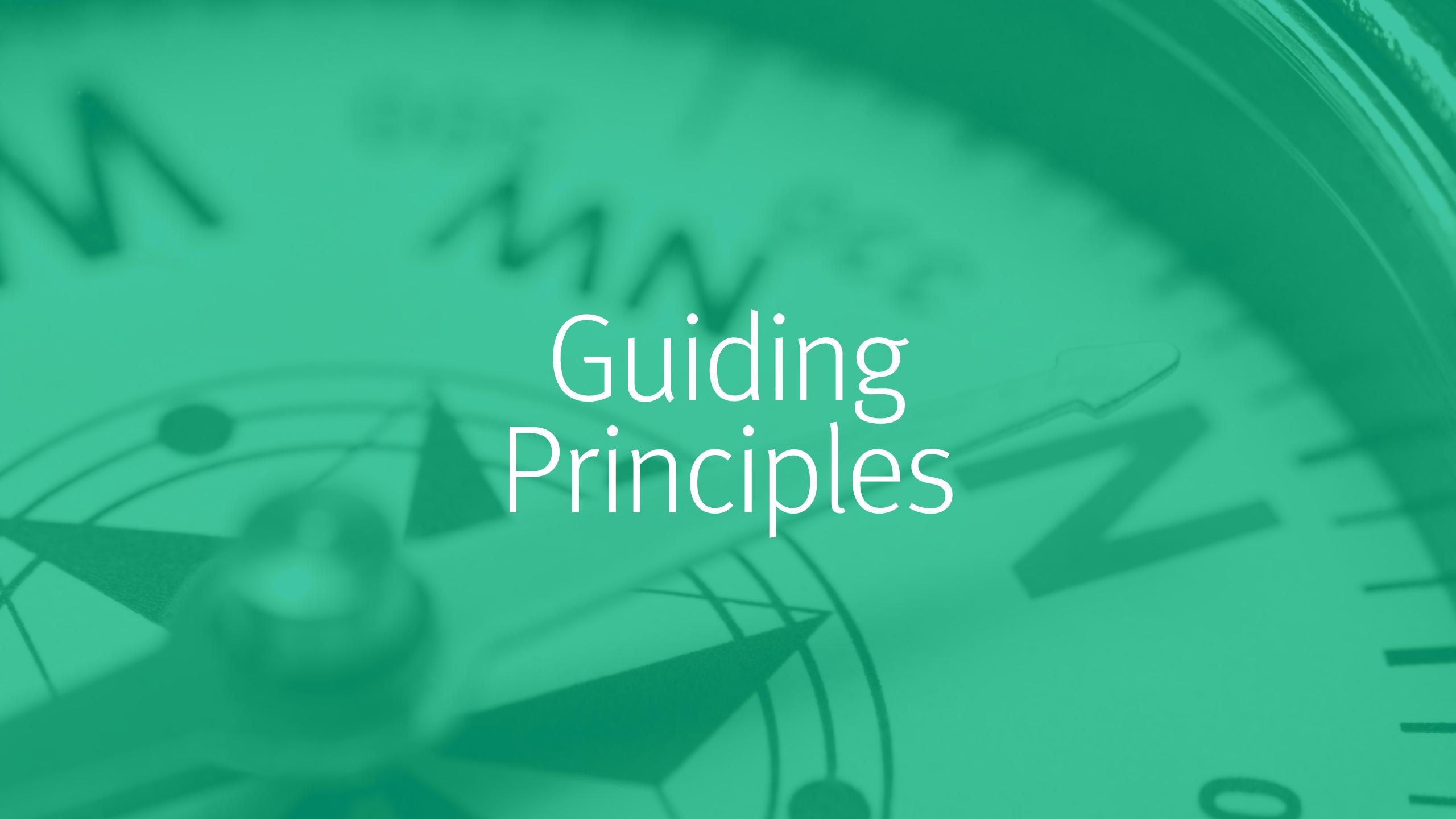
The US IRS form 990 tax return is available upon request at accounting@ilae.org



Congresses	47%	Academy	5%
Commissions	2%	Publications	44%
Dues, other	2%		

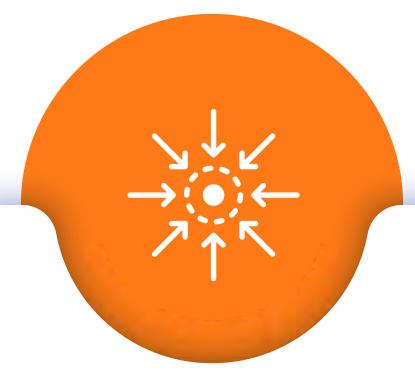






Guiding Principles

ILAE is working toward a world where no person's life is limited by epilepsy. Everything we do aligns with this vision, which is supported by a 10-year Strategic Plan and five guiding principles:



IMPACT

We strive to achieve international, enduring impact for individuals and communities affected by epilepsy



COOPERATION

We collaborate to generate shared outcomes



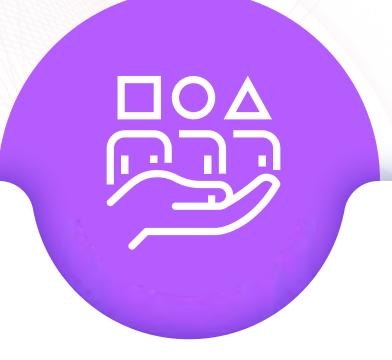
EXCELLENCE

We take a holistic and scientific approach to developing best practices



INTEGRITY

We aspire to the highest standards of conduct



INCLUSION

We work with all who strive for a world where no life is limited by epilepsy







