FULL LENGTH REPORTS
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- President’s & Vice President’s
- Education Council
- Congress Council
- Standards & Best Practice Council
- Global Advocacy Council
- Publications Council
- Commissions and Sections

www.ilae.org/reports
President’s Message
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.

J Helen Cross
ILAE President
Organization & Structure

The ILAE Executive Committee 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 Young Epilepsy Section and the Nursing Section — 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.
Organization & Structure

J Helen Cross
President, Chair, Congress Council

Robert Caraballo
Vice President

Alla Guekht
Treasurer, Chair, Global Advocacy Council

Edward Bertram
Secretary General

Sam Wiebe
Past President

Ingmar Blümcke
Chair, Education Council

Jean Gotman
Chair, Publication Council

Julie Hall
Executive Director ex officio

Eugen Trinka
Strategic Advisor ex officio

Jaideep Kapur
Chair, ILAE North America

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Eugen Trinka
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Jaideep Kapur
Chair, ILAE North America

ILAE Executive Committee 2021-2025

Francesca Sofia
IBE President ex officio

Gus Baker
IBE Secretary General ex officio

Graeme Shears
IBE Treasurer ex officio

Nathalie Jette
Chair, Standards & Best Practice Council

Jo Wilmshurst
Chair, ILAE Africa

John Dunne
Chair, ILAE Asia & Oceania

Ghaleb Eljandeel
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

Ghaleb Eljandeel
Chair, ILAE East Mediterranean
Organization & Structure

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.

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.
Organization & Structure

ILAE Staff and Support
Chapter Activities

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

Chad epilepsy consult session

Brazil national congress

Pakistan school epilepsy awareness
Chapter Activities

Democratic Republic of Congo
EEG training

Jordan
chapter congress

Kosovo
International Epilepsy Day

Mexico
national congress
Chapter Activities

Indonesia
International Epilepsy Day

Canada
annual fun run

Latin America
telemedicine meeting
Chapter Activities

El Salvador
International Epilepsy Day

Tanzania
radio outreach

Iraq
symposium
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
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 neurological disorders and their carers
- Gender, equity and human rights

Strategic objectives
- To 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

**Supporting Targets**
- 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

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

Level 1
Self-paced e-learning including case-based modules, covering basic principles in clinical epileptology.
Result: Level 1 certificate

Level 2
Blended learning: self-paced, patient-centered e-learning combined with adaptive learning formats and tutored courses (online or face-to-face) to build proficiency in epilepsy.
Result: Level 2 certificate

VIREPA
Highly interactive, e-modern online courses on EEG, epilepsy & sleep, neuromonitoring.
Result: Certificate of Completion

Resources
Supplemental reading and learning, including the interactive ILAE diagnostic manual, educational review papers, guidelines, and other publications related to the course content.
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.
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.

The ILAE e-Forum

Pre-session, open-access reading
Free webinar with case discussion
Post-session virtual case studies
3,854 total registrants in 2022
Five more planned for 2023!
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 care for epilepsy within the primary care setting. This curriculum can be used to shape future primary health care epilepsy education packages.

Click here to check out the new primary care curriculum, available in English and Spanish!
Congresses
Congress year in review
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 specifically on bridging gaps in services to small islands and remote areas.
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.
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.
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

- 5 congresses
- 10,204 delegates
- 600+ speakers
- 300+ sessions
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 Open™

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 Instagram post

Highest reaching Twitter post
Standards & Best Practice
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
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
Young Epilepsy Section
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
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
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.

Operational Expenses 2021

<table>
<thead>
<tr>
<th>Other Programs</th>
<th>10%</th>
<th>Academy</th>
<th>12%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Congresses</td>
<td>26%</td>
<td>Publications</td>
<td>10%</td>
</tr>
<tr>
<td>Regions</td>
<td>6%</td>
<td>Governance</td>
<td>3%</td>
</tr>
<tr>
<td>Commissions</td>
<td>7%</td>
<td>Administration</td>
<td>26%</td>
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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

### Operational Revenue 2021

- **Congressues**: 47%
- **Commissions**: 2%
- **Dues, other**: 2%
- **Academy**: 5%
- **Publications**: 44%
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