

# ANNUAL REPORT 2020

INTERNATIONAL  
LEAGUE  
AGAINST  
EPILEPSY **ILAE**  
ESTABLISHED 1908

## COLLABORATION & RESILIENCE



[WWW.ILAE.ORG](http://WWW.ILAE.ORG)



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# FROM THE PRESIDENT



*S. Mabe*

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2020 was a year like no other. Like other organizations, we were challenged to find new ways of doing things and fulfilling our mission to improve the lives of people with epilepsy around the globe.

In-person clinics shifted to telemedicine. Neurologists were called to care for COVID-19 patients. Many with epilepsy suffered interruptions in care and medication supplies. Research pivoted to SARS-CoV2 and its potential effects on people with epilepsy.

Every life was touched by the pandemic, many tragically. However, from isolation and uncertainty have emerged creativity and resilience.

Since 1909, ILAE has worked toward a world where no person's life is limited by epilepsy. Our work is ongoing, our optimism is persistent, and our resilience endures. We bring you this report as a summary of our efforts in 2020 as a global team of hundreds of dedicated volunteers and staff. Thanks to all of you for your time, effort, skills and compassion.

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A background image showing a microscopic view of virus particles, likely SARS-CoV-2, with orange, spiky surface proteins and a grey, textured core. The image is split diagonally, with the top right being white and the bottom left showing the virus particles.

# COVID-19: CHALLENGE & RESILIENCE

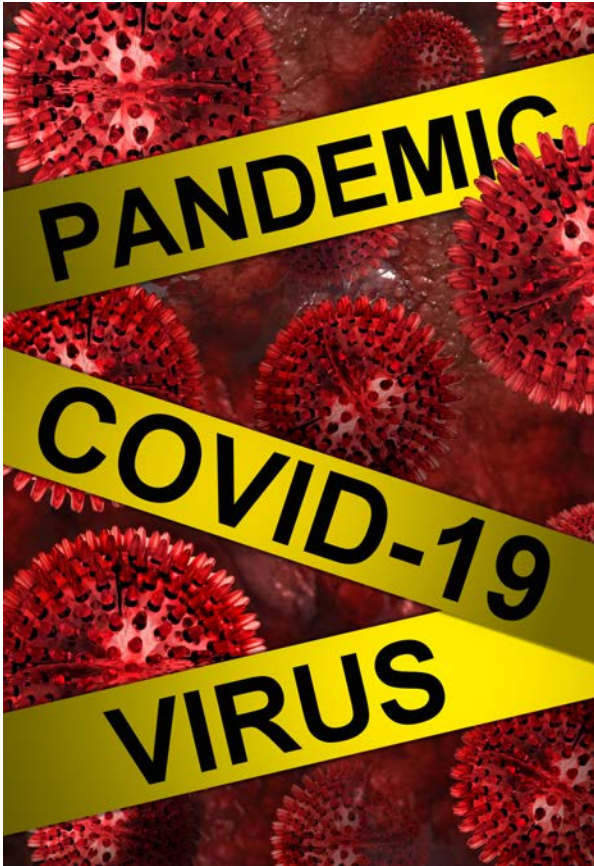
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The COVID-19 pandemic changed the entire health care world. As professionals who care for people with epilepsy, our initial concerns were whether COVID-19 could be associated with seizures or pose an increased risk for epilepsy, or whether people with epilepsy were at particular risk if they were infected with COVID-19. We also were concerned about the impact of the pandemic on mental health and access to care.

As the weeks went on, universities, clinics, and research laboratories were closed, and anticipated treatments and surgical evaluations were cancelled. Around the world, people with epilepsy were not able to access regular care. Some could not obtain the

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medications they needed to control their seizures.

While some providers could adapt and eventually provide telemedicine visits, many areas of the world did not have the resources or infrastructure to do so. In low- or middle income countries, treatment can be difficult to maintain during the best of circumstances; now, with job losses, social restrictions and other pandemic-related challenges, the inequality gap has widened.

With hospitals stretched beyond capacity, many of us

were called to care for patients with COVID-19. Some became infected, and not all survived.

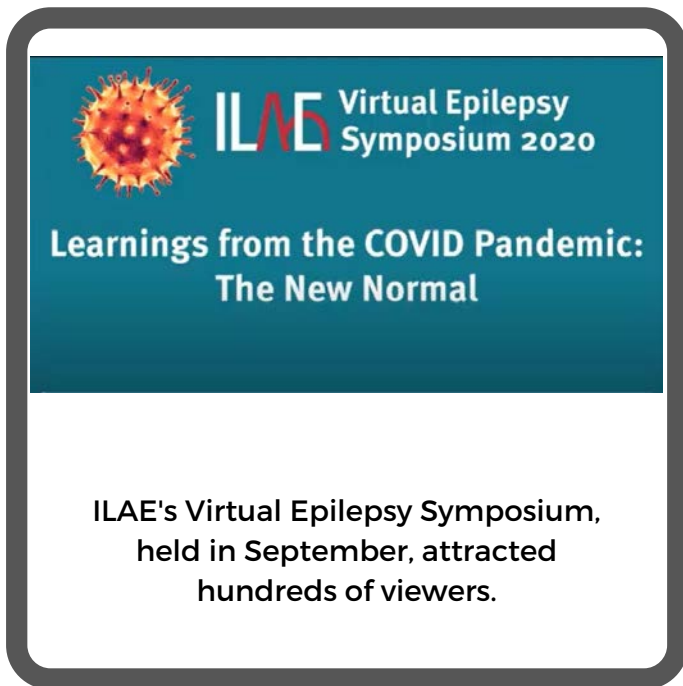
As 2020 came to an end, vaccinations were under way, and it appears we are starting to see light at the end of the tunnel. But most lower-resource countries have yet to receive vaccine shipments, and we cannot predict how much longer this will go on.

ILAE members continue to seek ways to help one another and to improve the care of people with epilepsy. The pandemic has exposed shortcomings and gaps in health systems, but also has provided an opportunity for us to reexamine our practices and priorities.

We end 2020 facing a delicate balance of finding gratitude and serenity where we can, while continuing to strive for better care for people with epilepsy around the world.



# COVID-19



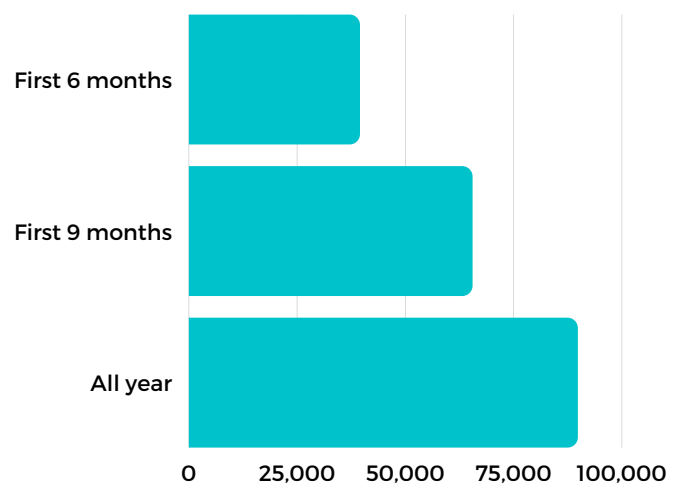
In addition to preparing manuscripts on COVID-19 and aspects of epilepsy care, the task force drafted and edited website information for clinicians, researchers, and patients and caregivers about the pandemic, SARS-CoV2, and effects on people with epilepsy. The group also drafted surveys and put out a call for case reports on COVID-19 in people with epilepsy. Many documents were translated into 10 or more languages.

The task force established competitive research prizes related to COVID-19 and epilepsy.

The ILAE website first launched content about the SARS-CoV2 virus and COVID-19 in March 2020. By the end of the year, COVID-19-related pages received nearly 90,000 visits.

ILAE's COVID-19 Task Force, chaired by treasurer J. Helen Cross, met semi-monthly throughout the year to discuss and address issues of COVID-19 infection in people with epilepsy, including access to care, access to medications, suspension of epilepsy monitoring unit and surgical evaluation activities, telemedicine, and quality of life issues.

## 2020: Cumulative visits to COVID-19-related pages on ILAE.org



# ORGANIZATION & STRUCTURE

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The ILAE's Executive Committee includes the President, Vice President, Secretary-General, Treasurer, and the Immediate Past President, as well as chairs of each region and council. Each Executive Committee serves for four years. The current committee will serve until August 2021.

The ILAE is organized into six regions, with chapters in more than 150 countries and territories. Our councils provide oversight and governance. Each has a specific purpose, based on functions defined by our mission and strategic plan. Topical commissions, committees, task forces and advisory commissions round out the ILAE's structure.

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# ILAE EXECUTIVE COMMITTEE



**Samuel Wiebe**  
President

Canada



**J. Helen Cross**  
Treasurer

United Kingdom



**Emilio Perucca**  
Past President

Italy



**Angelina Kakooza-Mwesige**  
Chair, ILAE-Africa

Uganda



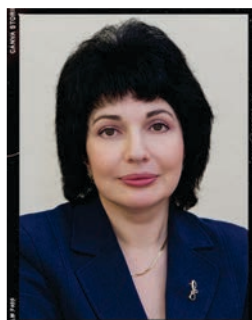
**Chahnez Charfi Triki**  
Chair, ILAE-Eastern  
Mediterranean

Tunisia



**Roberto Horacio  
Caraballo**  
Chair, ILAE-Latin  
America

Argentina



**Alla Guekht**  
Vice President

Russian Federation



**Edward Bertram**  
Secretary General

United States



**Jean Gotman**  
Strategic Advisor

Canada



**Akio Ikeda**  
Chair, ILAE-Asia-Oceania

Japan



**Eugen Trinko**  
Chair, ILAE-Europe

Austria



**Nathalie Jette**  
Chair, ILAE-North  
America

United States



# ILAE EXECUTIVE COMMITTEE



**Julie Hall**  
Executive Director  
  
United Kingdom

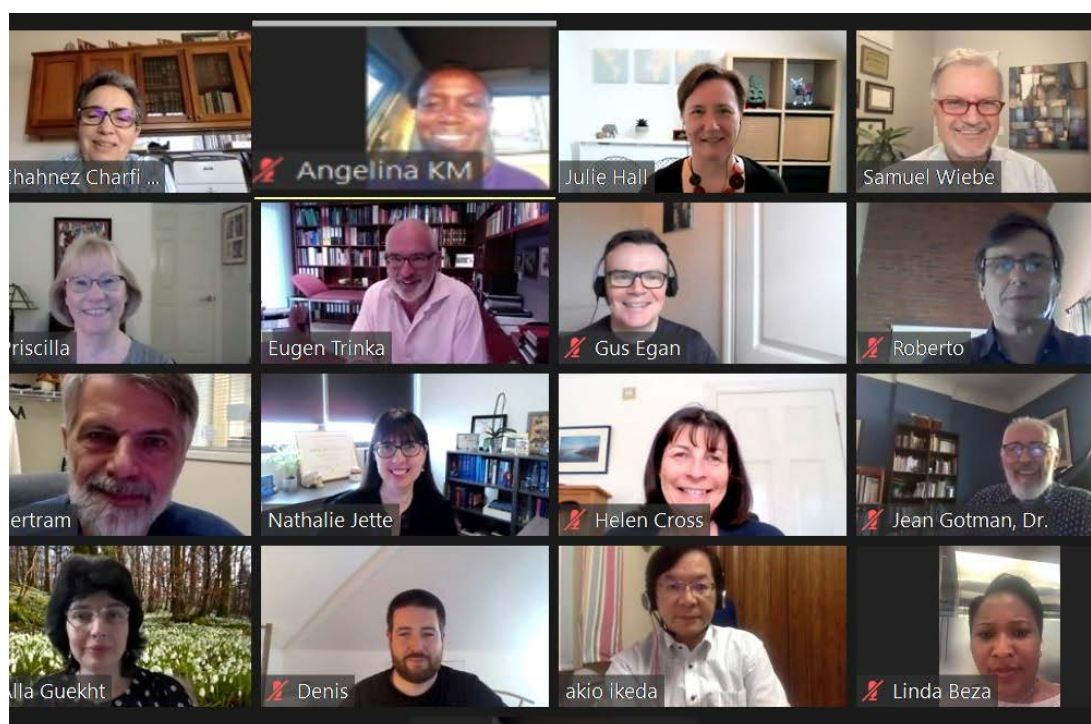
**Ingmar Blümcke**  
Chair, Education Council  
  
Germany

**Mary Secco**  
Secretary General,  
International Bureau for  
Epilepsy (IBE)  
  
Canada



**Shichuo Li**  
Advisor on Public Health  
  
China

**Martin Brodie**  
President, International  
Bureau for Epilepsy (IBE)  
  
United Kingdom



Executive Committee meeting virtually

# REGIONS

Each of ILAE's six regions has similar goals:

- Strengthen education and training
- Promote research
- Increase epilepsy awareness
- Address barriers and issues that affect epilepsy diagnosis and treatment

Initiatives and programs include:

- In-person and virtual training courses
- Educational webinars
- Fellowships
- Community awareness projects
- Research and publications
- Advocacy and public policy liaisons with local and national government





# REGIONAL HIGHLIGHTS

## AFRICA

- Successful partnerships with regional epilepsy associations
- Offers Pediatric Epilepsy Training (PET) courses and other educational opportunities
- Has established strong communication channels, including a regional newsletter, WhatsApp group, and email groups

## ASIA-OCEANIA

- Conducted video EEG workshop and exams in Malaysia (pre-pandemic)
- Developed joint statement on safe and affordable epilepsy surgery (Western Pacific Regional Office of WHO, in collaboration with ILAE and IBE)
- Produced publications on stigma, closing the epilepsy management gap, HLA screening for AED sensitivity

## EASTERN MEDITERRANEAN

- Initiated a webinar series in August 2020, in English and French
- Establishing an online EEG tool and supporting website to improve training and disseminate information
- 94% of chapters conduct national and/or regional activities
- Administers fellowships and visiting professor programs (suspended in 2020)

## EUROPE

- Conducts 10+ educational courses/trainings every year
- 2020 Regional Congress moved to 2022; will be held in Geneva
- Multiple collaborations with European Academy of Neurology (EAN)
- Initiated a successful webinar series that attracted viewers from >95 countries

## LATIN AMERICA

- Awards 14 one-year clinical epilepsy fellowships
- Offers Regional Congress-associated training courses
- Administers fellowship program with Western University (Canada)
- Developed an epilepsy education program for schoolteachers that reached >6,000 educators
- Epilepsy Week activities are held in many countries in the region

## NORTH AMERICA

- Hosted ILAE's first virtual congress (see page 30)
- Established a Global Health database to centralize project information from around the world
- Established the Canada to Trinidad & Tobago Project to improve care in the Caribbean, including virtual clinics and training opportunities

# COUNCILS

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Our councils are ongoing entities responsible for long- and short-term planning, policy review, and recommending a course of action to the Executive Committee.



**EDUCATION COUNCIL** - Chaired by Ingmar Blumcke, this council oversees ILAE's online courses (VIREPA) and the ILAE Academy, as well as other educational activities and collaborations.



Launched the ILAE Academy, an online portal providing educational modules on all aspects of epilepsy care and treatment (page 18)

**CONGRESS COUNCIL** - Chaired by J. Helen Cross, this council oversees all aspects of ILAE congresses, including needs assessments, organization and composition, collaboration, and enhancements.



Developed and hosted the first all-virtual congress in ILAE's 111-year history, with 526 registrants from all over the world (page 30)

**GLOBAL ADVOCACY COUNCIL** - Chaired by Alla Guekht, the council oversees strategies to enhance the quality, relevance, and profile of ILAE's advocacy activities, including working with other organizations and developing reports and declarations.



Years of global effort resulted in the unanimous passing of a World Health Organization resolution to create a 10-year Intersectoral Global Action Plan on epilepsy (page 26)

**PUBLICATION COUNCIL** - Chaired by Jean Gotman, the council oversees publications and media products, including strategies to enhance quality and relevance, innovations, sustainability, and policy.



2020 brought increased journal impact, and more journal pages were produced. The ILAE website saw a 19% increase in visits since 2019 (page 20).

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# COMMISSIONS AND TASK FORCES

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Topic-oriented commissions are appointed by the president every four years. Current commissions:

- Diagnostic Methods
- Epidemiology
- Genetics
- Medical Therapies
- Neurobiology
- Pediatrics
- Psychiatry
- Surgical Therapies
- ILAE-Lancet Neurology Commission
- Young Epilepsy Section (YES)

## Selected Task Force accomplishments

**Neonatal Seizures:** Developed modifications to the ILAE classifications of seizures and epilepsies for neonatal seizures. Position paper expected for publication in early 2021.

**Research Advocacy in Children:** Completed data collection for a systemic review on 30 years of epilepsy research in Africa. More than 1,200 records were included in the initial analysis.

**EEG:** Completed strategic planning and a detailed proposal

for the development of a web-based, interactive, international EEG atlas for education and research. The project is a collaboration with the International Federation of Clinical Neurophysiology (IFCN).

**Access to Treatment:** Conducted multiple surveys on access to and costs of anti-seizure medications, receiving data from more than 100 countries.

**Psychology:** Published an updated Cochrane review on psychological treatments in epilepsy.

**Driving:** New in 2020, this task force compiled an inventory of driving standards, defined gaps in the area of driving research/policy, and is working to develop driving standards.

**Identification, Treatment and Prevention:** Developed first-ever clinical practice guidelines for the treatment of depression in adults with epilepsy.

**Young Neurobiologists:** Received a pilot grant to help establish a Master's program in epilepsy as part of the European Universities Initiative. We support project activities and program development through our Commission on Neurobiology and our Education Council.

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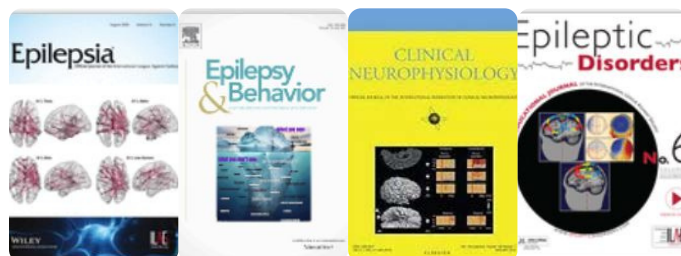
# SELECTED TASK FORCE & REGIONAL PUBLICATIONS

**Establishing criteria for pediatric epilepsy surgery center levels of care: Report from the ILAE Pediatric Epilepsy Surgery Task Force.** Gaillard WD et al.,  
Epilepsia

**Perceptions of adult and child neurologists of transition programs in epilepsy in Latin America: A cross-sectional study.** (ILAE-Latin America) Carrizosa-Moog J, et al. Epilepsy & Behavior

**Driving a motor vehicle and psychogenic nonepileptic seizures: ILAE Report by the Task Force on Psychogenic Nonepileptic Seizures.** Asadi-Pooya AA et al., Epilepsia Open

**Global Survey of Guidelines for the Management of Epilepsy in Pregnancy: A report from the International League Against Epilepsy Task Force on Women and Pregnancy.** Tomson T et al., Epilepsia Open



**Acute symptomatic seizures secondary to autoimmune encephalitis and autoimmune-associated epilepsy: Conceptual definitions. (ILAE Autoimmunity and Inflammation Task Force)** Steriade C et al., Epilepsia

**ILAE Neuroimaging Task Force highlight: Review MRI scans with semiology in mind.** Federico P et al., Epileptic Disorders

**Epigenetics explained: a topic "primer" for the epilepsy community by the ILAE Genetics/Epigenetics Task Force.** Kobow K et al., Epileptic Disorders

**MRI essentials in epileptology: a review from the ILAE Imaging Taskforce.** Wang I et al., Epileptic Disorders

**Standard procedures for the diagnostic pathway of sleep-related epilepsies and comorbid sleep disorders: an EAN, ESRS and ILAE-Europe consensus review.** Nobil L et al., European Journal of Neurology



# ILAE STAFF MEMBERS



**Julie Hall**

Executive Director



**Donna Cunard**

Accountant



**Kathryn Hodgson**

Senior Program Manager, Asia & Oceania



**Haitian Power**

Finance Manager



**Priscilla Shisler**

Director of Engagement & Education



**Gus Egan**

Chapter & Membership Development Manager



**Denis McEvoy**

Congress Director



**Finola Quinn**

Senior Program Manager, Europe



**Nancy Volkers**

Communications Manager



**Eva Biesel**

ILAE Academy



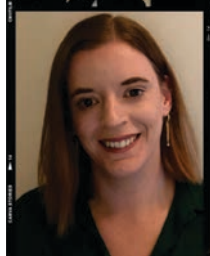
**Deborah Flower**

Web & Social Media Manager



**Alma Paez**

Program Manager, Latin America



**Siobhan Shannon**

Program Manager, North America

**ILAE staff appreciate:** The inspiring **people** we interact with every year + Always **learning** something new + Working with a great **team** and experts around the world + Supporting volunteer leaders whose **commitment** to ending the suffering from epilepsy is exceeded only by their **compassion** + Learning about new **advances** in the field + Participating in **innovative** educational efforts + Being part of an organization that **makes a difference**



# EDUCATION & TRAINING

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Education is a primary focus for ILAE, as we aim to bring knowledge and expertise in epilepsy to any health professional around the world who desires it. In 2019, ILAE established a competency-based curriculum for international education that addresses seven domains of learning at three levels of expertise.

2020 brought the launch of the ILAE Academy as well as the development of an epilepsy curriculum for primary care providers. Two ILAE regions established webinar series, and ILAE endorsed several outside educational activities that aligned with our mission and goals.

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# THE ILAE CURRICULUM

The curriculum provides a framework for all of ILAE's educational offerings, from formal courses to online webinars.

## The learning domains:

- Diagnosis
- Counseling
- Pharmacological treatment
- Epilepsy surgery
- Emergencies
- Comorbidities
- Biology of epilepsy

# 124

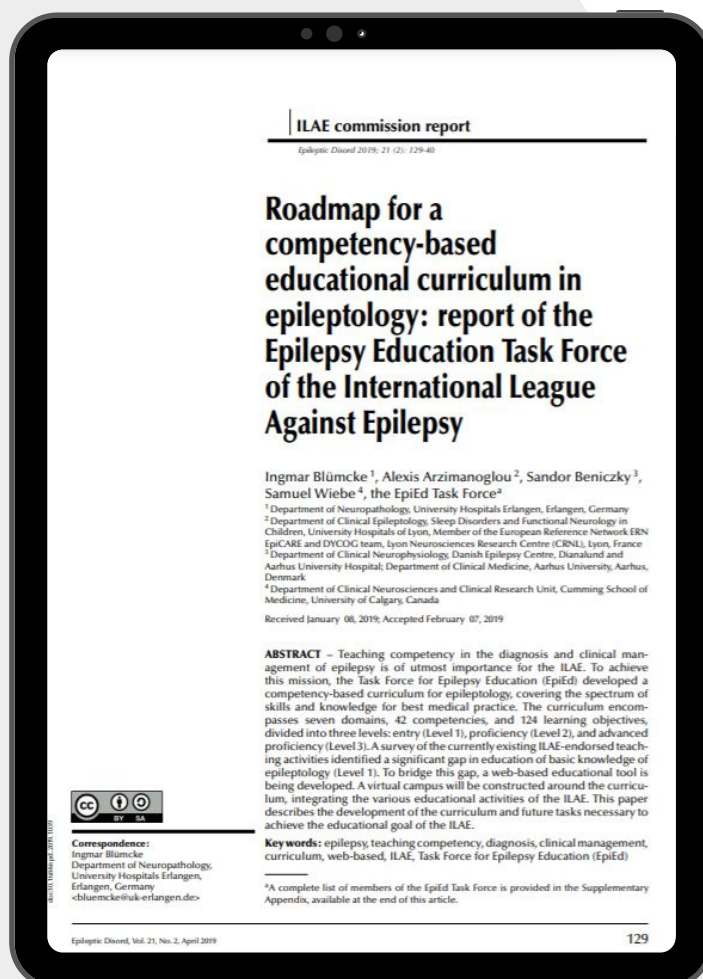
Learning  
objectives

# 42

Competencies

# 7

Domains





# Academy Launch!

Early in 2019, ILAE finalized a global epilepsy curriculum designed to educate professionals in epileptology at three levels: Entry level, proficiency, and advanced proficiency. The curriculum provided the cornerstone for the ILAE Academy, a virtual campus designed to provide opportunities for epilepsy education to learners throughout the world. Launched in July 2020, the online Academy allows registered users to advance their knowledge of epilepsy at their own pace, track their progress and earn certificates.



**1,690**  
Course  
completions

**63**  
Countries

**11**  
Case studies



# Virtual Education: An ILAE Standard

## Virtual Epilepsy Academy

ILAE's VIRTual EPilepsy Academy (VIREPA) began as an initiative of the Commission on European Affairs and was formally incorporated into ILAE educational activities in 2009.

VIREPA offers six-month, practice-oriented courses relating to the diagnosis and treatment of epilepsy across a broad range of topics,

Participant evaluations are consistently and overwhelmingly positive regarding new knowledge gained and the relevance of the courses to professional practice. Current course topics include EEG in the diagnosis and management of epilepsy, and epilepsy and sleep.



## Webinars

ILAE was among the first international medical organizations to recognize the potential of e-learning in postgraduate education. For more than 15 years, we have worked to develop and implement these educational resources to achieve our educational mission. The pandemic halted in-person learning opportunities worldwide, increasing the demand for virtual educational opportunities.

In mid-2020, ILAE-Eastern Mediterranean established a series of webinars in French and English, covering topics such as neurostimulation and anti-seizure medication selection. Fourteen webinars were produced and aired, and the series was expected to continue well into 2021.

### VIREPA 2020

840 Students

88 Countries

>93% Satisfaction



# PUBLICATIONS & COMMUNICATION



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Our publications and communications became lifelines for those isolated and quarantined during 2020.

ILAE's four journals, as well as our website, social media channels, and email communications, strived to keep people informed of the constantly changing pandemic landscape and how it was affecting epilepsy research and care.

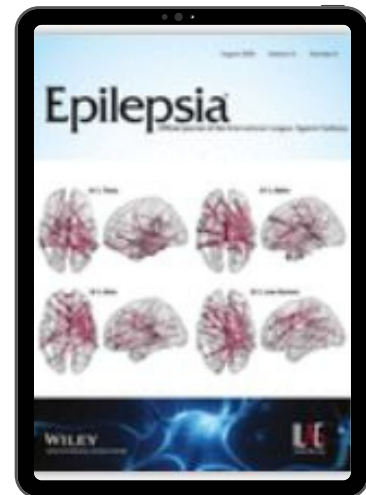
We manage both internal and external communications, reaching members, potential members, and the interested public from every corner of the globe.

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# JOURNALS

First published in 1909, **Epilepsia** is the leading, authoritative source for innovative clinical and basic science research for all aspects of epilepsy and seizures. The journal publishes critical reviews, opinion pieces, and guidelines that foster understanding and aim to improve diagnosis and treatment.



2020 marked the 5-year anniversary for **Epilepsia Open**, our open access journal, which publishes rigorous basic and clinical epilepsy research or critical reviews aiming to promote the dissemination, transparency, translatability, and implementation of epilepsy research advances.



## 6.040

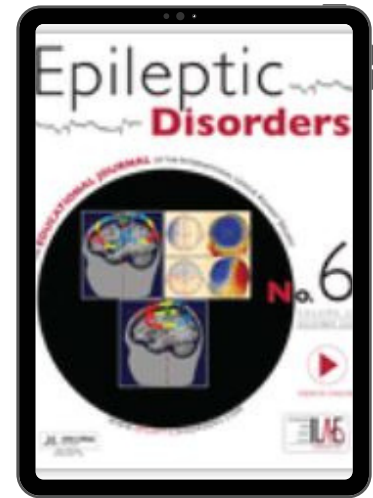
*Epilepsia's* impact factor in 2020

## 38.8%

Increase in downloads of *Epilepsia Open* articles since 2019

# JOURNALS

**Epileptic Disorders** focuses on high-quality, educational content related to all aspects of epilepsy, including diagnosis, natural history, and management. This journal has been online-only since 2018.



**Epigraph** is our online news journal. Started in 1999, Epigraph publishes timely, news-style articles on all aspects of epilepsy. Compared with 2019, traffic to Epigraph articles on the ILAE website increased 44% in 2020.



## 39%

Increase in *Epileptic Disorders* page production since 2019

## 75,272

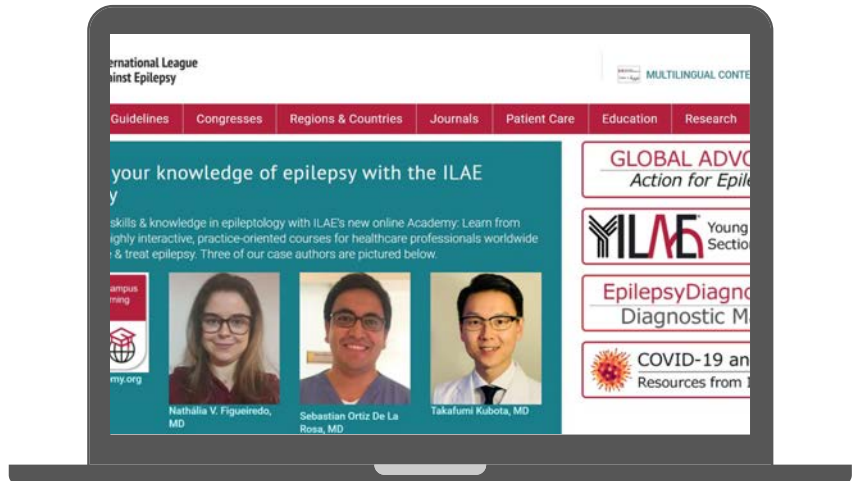
Visits to *Epigraph* article pages in 2020

# PUBLICATIONS

The ILAE website served as a crucial point of contact for information about COVID-19 and epilepsy, while continuing to keep chapters and members updated on news, events, and recent publications.

Regular email newsletters and social media postings linked users to website pages, which received more than 1.37 million views in 2020, a 19% increase from 2019. Traffic originated in 222 countries, areas and territories.

The ILAE Wikipedia Project has identified about 200 articles for potential updates. More than two dozen have been prioritized and the project's leaders are creating a community of writers and peer reviewers.



**ILAE**  
Wikipedia  
Project

**19%**

Increase in website  
traffic since 2019

**64**

ILAE web pages with  
information about  
COVID-19



## SOCIAL MEDIA



**40,813**  
likes, comments,  
& shares



**1,270**  
people reached  
per day



**1,640**  
followers



**92%**  
increase in  
subscribers



# GLOBAL ADVOCACY



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In November 2020, the longstanding efforts of the ILAE, the International Bureau of Epilepsy, and the World Health Organization—with support from WHO member states, the World Federation of Neurology, and the European Federation of Neurological Associations—culminated in the unanimous approval of a WHO resolution to create and implement an **Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders**.

This unique achievement is built on more than two decades of collaboration and effort. It offers an extraordinary opportunity to work toward ILAE's goal of ensuring that no person's life is limited by epilepsy.

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# 73rd WORLD HEALTH ASSEMBLY



**The World Health Assembly is the decision-making body of the WHO. It includes delegates from all WHO Member States who discuss and vote on specific agenda items prepared by the WHO Executive Board. The 73rd WHA was held in May 2020 and November 2020 in virtual format, due to the COVID-19 pandemic.**

Before the November meeting, an intense period of activity to create a draft resolution was undertaken by the Russian Federation, co-sponsoring Member States, WHO secretariat, ILAE, IBE, and other collaborators. The activity included the first-ever side event on epilepsy, held in May 2019. Side events, held alongside each WHA, provide an opportunity to highlight specific health care domains to WHO leadership and top-level health authorities worldwide.

The draft resolution recognizes that epilepsy and other neurological disorders are the leading cause of disability-adjusted life years

Delegations that made official statements in support of the Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders

**Russian Federation | Australia | Bahrain | Belarus | Bhutan | Canada | China | Colombia | Eswatini | European Union and its Member States | Guyana | Iceland | Jamaica | Mexico | Philippines | Sri Lanka | United States of America | Uruguay**

Note: Countries shown in bold requested to co-sponsor the Resolution.

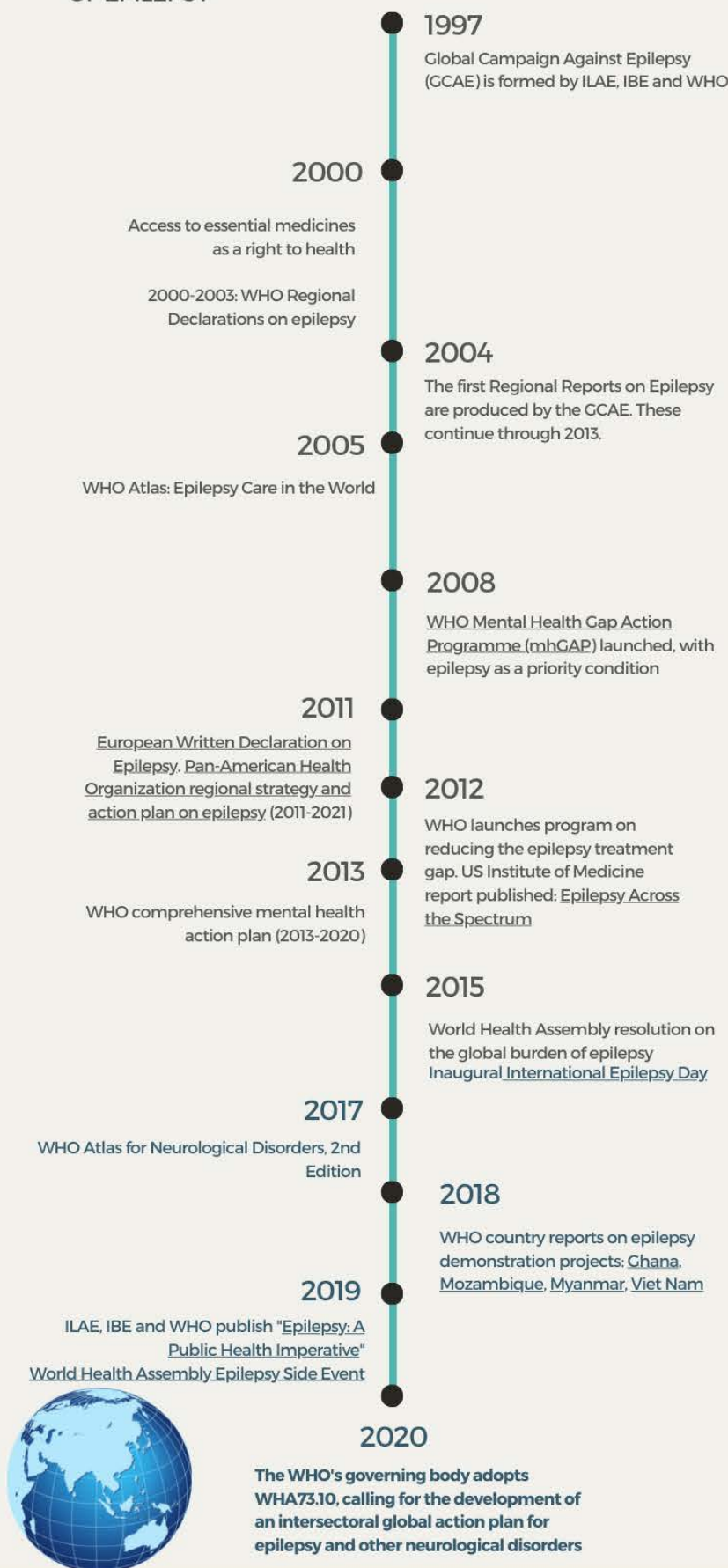


and the second leading cause of death worldwide, and that epilepsy and other neurological disorders disproportionately impact people living in low- and middle-income countries. It notes with concern that the risk of premature death in people with epilepsy is three times higher than in the general population. It highlights that epilepsy is a highly treatable condition and that over 70% of people with epilepsy could live seizure free if they had access to appropriate treatment.

The Resolution also notes that epilepsy and other neurological and mental health disorders often co-exist and can be compounded by other health conditions, and that epilepsy can be caused by stroke, traumatic brain injury, and other neurological disorders.

## A HISTORY OF INITIATIVES TO REDUCE THE GLOBAL BURDEN OF EPILEPSY

COLLABORATION AMONG ILAE, IBE AND THE WORLD HEALTH ORGANIZATION HAS BEEN A LEADING FORCE IN ADDRESSING THE BURDEN OF EPILEPSY WORLDWIDE.

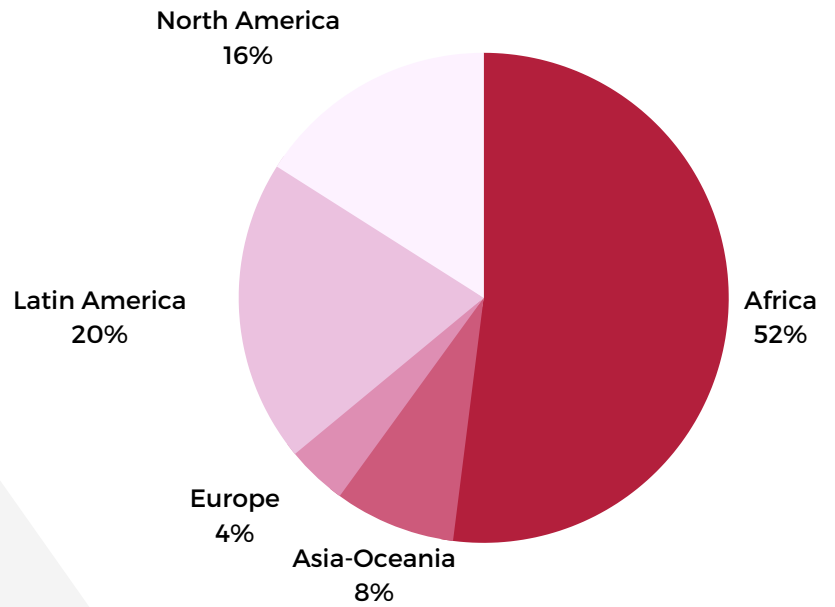


# GLOBAL HEALTH DATABASE

ILAE's [Global Health In Epilepsy Database](#) aims to capture programs and research initiatives from all over the world attempting to reduce the epilepsy treatment gap. By identifying and virtually connecting programs that are physically thousands of miles apart, the database seeks to increase collaboration, reduce redundancies, amplify impact, and offer service opportunities.

Researchers are encouraged to add their projects to the database by visiting [our website](#).

## Projects by region





# CONGRESSES



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The upheaval brought about by the COVID-19 pandemic in decimated ILAE congresses in 2020. Of the four planned congresses for the year, only the North American congress was held, shifting to a virtual format. Regional congresses for Asian & Oceania, Europe and Latin America were postponed.

While every organization shifted in-person conferences online, NAEC was ILAE's first wholly virtual congress. Would it be successful?

Planning took a great deal of effort and creative spirit. "Virtual congresses have brought difficulty and opportunity in equal measure," said Congress Director Denis McEvoy. "Defining the core elements of our congresses and transforming them to a virtual format required extensive research and development. But by far, the biggest benefit has been the increased potential reach."

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# NORTH AMERICAN EPILEPSY CONGRESS 2020

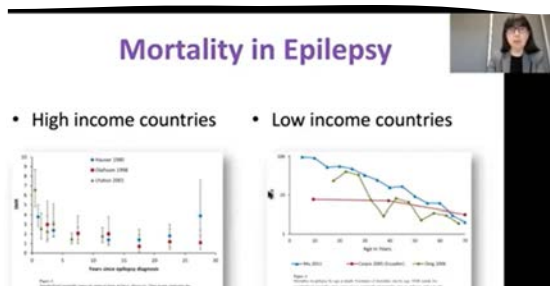
In some ways, virtual congresses leveled the playing field, offering sessions to people around the world without the significant costs of travel and accommodations.

On-demand viewing allows people to attend at their own convenience, without having to take time off work.

However, access issues remain. People with disabilities and those with poor internet connections may not be able to participate in a virtual meeting. Non-fluent English speakers may find virtual meetings more difficult to follow, as body language and other context is missing, compared with face-to-face congresses.

If access issues can be managed sensitively, virtual congress participation provides an opportunity for ILAE to expand its reach to provide education, networking, and advocacy opportunities to people around the globe.

- **FIRST** ILAE congress in the North American region
- **FIRST** of ILAE's congresses to go virtual in response to the COVID-19 pandemic
- **FIRST** congress to offer on-demand viewing of sessions after the meeting's end



# NAEC Kudos



William Lo @williamblo · Sep 24, 2020

Attending the virtual [#NAEC2020](#) at home. Would've been better to see my colleagues and friends in person, but nothing can stop our continuous effort to further our knowledge and deliver epilepsy treatment.

"Nothing can stop our...effort to further our knowledge and deliver epilepsy treatment."

"Epilepsie Outaouais est très heureux de participer aux conférences internationales offerts par ILAE"



Épilepsie Outaouais @EpilepsieO · Sep 24, 2020

Épilepsie Outaouais est très heureux de participer aux conférences internationales offerts par ILAE - International League Against Epilepsy. [#NAEC2020](#)



Mark McAllister @McAllister\_Mark · Sep 24, 2020

Congrats to the [@EpilepsyCongres](#) and thanks for including me in the [#NAEC2020](#) conversation today. Great chatting with [@KellyGC411](#) about her personal experience and advocacy work!

"Congrats to the [@EpilepsyCongress](#)"

"Great talks"



Jorge G Burneo @epileptologo · Sep 26, 2020

Great talks by [@wiebe\\_ilae](#), Amza Ali and Sheryl Haut at the [#NAEC2020](#) on the current situation of [#epilepsy](#) care in North America [@ilaeWeb](#)



Kadam Lab @KadamLab · Sep 24, 2020

Excited to be speaking about the labs [#SYNGAP1](#) research at the [#NAEC2020](#) virtual conference this weekend Date & time: Saturday 26 September 18.45 - 19.45  
Session: Novel mechanisms of epilepsy and intellectual disability

"Excited to be speaking .... at [#NAEC2020](#)"

"First North American Epilepsy Congress is a huge success."



Olga Selioutski @OSelioutski · Sep 27, 2020

First North American Epilepsy Congress is a huge success. Incredible line up of topics and speakers! [#NAEC2020](#)

**500+**  
attendees

**22**  
sessions

**94%**  
satisfaction

# NURTURING LEADERS



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A crucial part of ILAE's engagement activities revolve around younger members – the next generation of international epilepsy leaders and experts.

Our **Leadership Development Program**, started in 2015, gives younger members a unique opportunity to receive leadership training, guidance and support in conjunction with attending one of ILAE's congresses. Each program accepts about 30 people.

In 2017, we established the **ILAE Mentor/Mentee Program**, matching trainees with mentors in their area of clinical or research interest.

In 2018, ILAE's **Young Epilepsy Section (YES)** held an organizational meeting in London, attracting interested members from around the world. Since then, YES has grown to more than 570 members and established national chapters in several countries.

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# YOUNG EPILEPSY SECTION



Board:



**Marion Galovic, chair**



**Christos Lisgaras, vice chair**

Working alongside ILAE leaders and staff gives me a unique opportunity to learn from the best. I appreciate how welcome they are to new and sometimes overambitious ideas!



**Genevieve Rayner, secretary**



**Katja Kobow, treasurer**

Regional representatives:



**Naluca Mwendaweli**  
Africa



**Mohmad Farooq-Shaikh**  
Asia/Oceania



**Reem Alyoubi**  
Eastern Mediterranean



**Caroline Neuray**  
Europe



**J. Sebastian Ortiz de la Rosa**  
Latin America



**Ruta Yardi**  
North America

YES is a global melting pot where early-career epilepsy professionals can share ideas and learn from one another. I very much enjoy being a part of this network!

# YOUNG EPILEPSY SECTION

In 2019, scarcely one year after it was formed, YES organized a robust slate of popular sessions at the 33rd International Epilepsy Congress in Bangkok, including brainstorming workshops, career development talks, and even yoga breaks. The group also launched a peer-to-peer mentoring program, matching experienced postdocs and fellows with younger colleagues.

In 2020, YES persevered despite the pandemic. Members in Latin America launched a webinar series, producing 22 educational videos that attracted more than 30,000 views. The group also continued to manage Facebook and Twitter accounts in six languages, and began translating ILAE and IBE materials into languages other than English,



Nama-stay involved with YES

# 24

**board  
meetings**

# 570

**registered  
users**

# 21,000

**internal  
communications**

# FINANCIALS



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In last year's annual report, we announced a milestone: reaching a \$20 million endowment. Relying on expertise from non-medical volunteers, we developed an investment policy and strategy to meet that goal with the intent of using the investment revenue to develop new projects and initiatives during the good years and to cover operational costs during the lean years.

Given the 2020 economic impact of the pandemic, reaching our endowment goal could not have happened at a more opportune time. The endowment provided us the financial stability and security to move forward

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# FINANCIALS

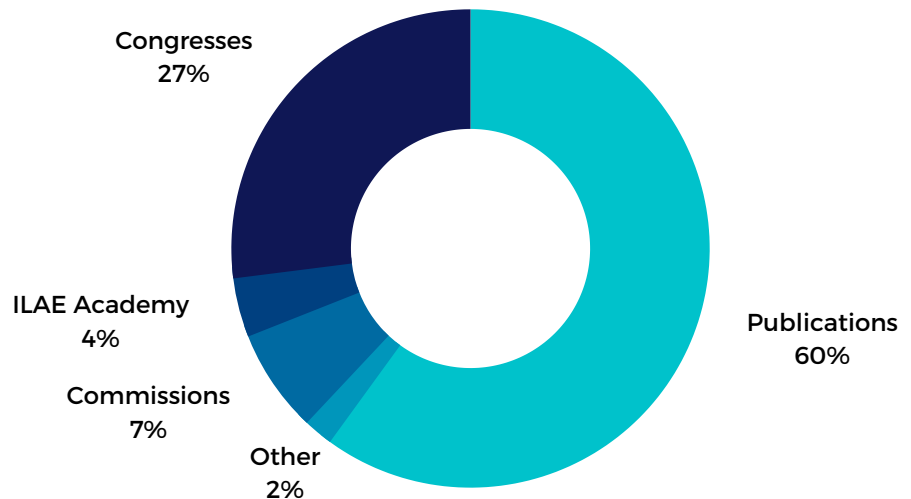
with planned initiatives, despite the postponement of our larger congresses.

In 2019, ILAE journals provided the major operational revenue source, primarily from royalties. Journal revenue supported our administrative expenses, as well as commission and task force activities. 2019 ended with an operational deficit that was offset by strong investment earnings.

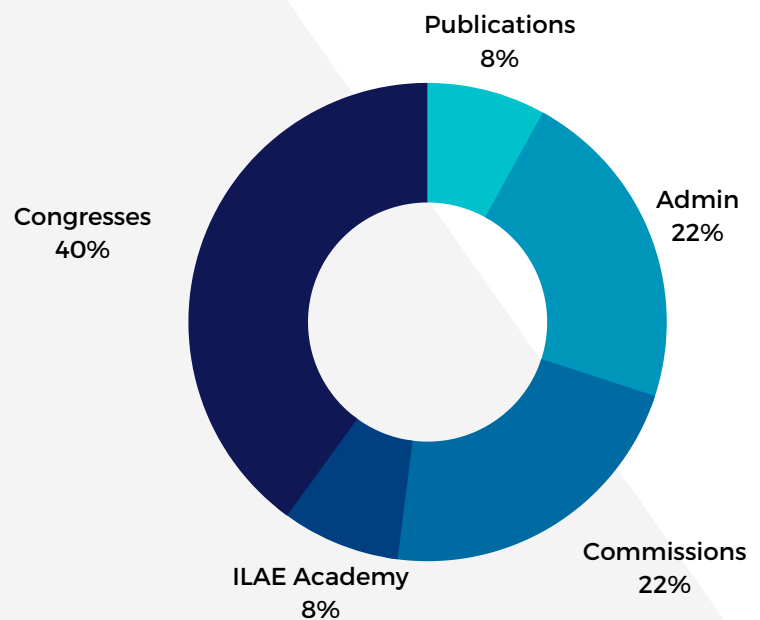
Important decisions made in 2019 have re-shaped and enhanced our organization. In April 2020, we established the ILAE Secretariat, an office in Dublin responsible for planning and managing our congresses and events. We also hired Julie Hall as ILAE's first executive director. She will oversee the US headquarters and the Dublin office.

July 2020 brought the launch of the ILAE Academy (page 18), offering a virtual curriculum with a global reach. This launch happened at an opportune time, given the pandemic. The endowment and journal revenue, as well as extensive planning, allowed these initiatives to move forward.

## Operational Revenue - 2019



## Operational Expenses- 2019



# FINANCIALS

With the emergence of the pandemic and the accompanying global travel restrictions, our activities and budgets were restructured and reorganized.

With the emergence of the pandemic and the accompanying global travel restrictions, our activities and budgets were restructured and reorganized. Courses, summer schools and meetings were postponed or held entirely virtually.

While two of the congresses, the European and the Latin American congresses, were postponed, we decided to hold our first fully virtual congress in September 2020: the North American Congress (page 29). This successful event is providing the basis for virtual congresses in 2021 and beyond. We will continue to collaborate with the International Bureau of Epilepsy and to offer a strong scientific program in a fiscally responsible manner.

We are grateful to the commissions and task forces for their ongoing work; in particular, we thank the chairs for being responsive to financial issues and for careful planning. We also extend thanks to the Budget Committee, which puts in many hours at the end of each year, as well as the volunteers on the Financial Advisory Committee.

**April**

ILAE Secretariat  
established

**June**

Executive director  
hired

**July**

ILAE Academy  
launch

**September**

First virtual congress

# ON TO 2021



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**N**ext year, we see increased focus on developing evidence-based guidance, as well as continued growth in learning opportunities. The development of the Intersectoral Global Action Plan (page 25) provides an unprecedented opportunity to promote epilepsy as a public health imperative, as well as strengthen services for other neurological disorders and comorbid conditions. Though the pandemic's financial and travel restrictions will continue, our capability for virtual collaboration should strengthen global reach as we advance our guiding principles: cooperation, excellence, integrity, inclusion, and above all, impact.

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# VISION, MISSION, GUIDING PRINCIPLES

## OUR VISION

**ILAE's vision is a world in which no person's life is limited by epilepsy.**

## OUR MISSION

**ILAE will ensure that health professionals, people living with epilepsy and their care partners, governments and the public worldwide have the resources and tools needed to understand, prevent, diagnose, and treat epilepsy. ILAE will achieve this by identifying needs, setting standards, providing education, advocating for access to care and treatment and facilitating research.**



## OUR 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.



<https://www.facebook.com/ILAE.Epilepsy/>



<https://twitter.com/IlaeWeb>



@ilae\_epilepsy

Working toward a world in which no person's life is limited by epilepsy

Full annual report information:

<https://www.ilae.org/about-ilae/ilae-reports>