

INVITED COMMENTARY

The ILAE at 110—Reflections on the last decade

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One hundred and ten years ago, on August 30th 1909, the International League Against Epilepsy (ILAE) was born in the Donau room of the Bristol Hotel in Budapest. Its stated mission at inception was to devote itself to people with epilepsy and to find means for prevention, treatment and rehabilitation in epilepsy. The accompanying article by Simon Shorvon in this issue of *Epilepsia Open*, masterfully narrates the League's development during its first 100 years, a century of extraordinary growth and transformation. Our purpose is to highlight some aspects of the League's life in the ten years following its one hundredth birthday, a decade of continued achievements and challenges.

1 | THE UNDERPINNINGS: A STRATEGIC PLAN AND THE ROLE OF THE WORLD REGIONS

One of the first initiatives of the last decade was the creation in 2009 of a strategic plan for the League. Forty experts from twenty countries and international organizations assembled to construct a broad roadmap which continues to guide the League's role as the world's premier international resource for knowledge, innovation, and care in epilepsy, and for its financial sustainability [www.ilae.org/files/dmfile/StrategicPlan-FinalJuly-09.pdf]. With the creation in 2010 of the ILAE African Commission in Senegal, all world regions acquired formal representation in the League. It became increasingly

clear that the international constituency required access to the decision-making process of the League's affairs. To this end, the Constitution was amended in 2011 to include elected Chairs of each Regional Commission of the world as voting members of the Executive Committee. The Regional Commissions have since evolved to constitute the ILAE Regional Board, which now represents 119 member chapters in as many countries, and forms an integral component of the League's governance.

2 | LOOKING OUTWARD TOGETHER

The atmosphere created by unprecedented speed of communications, the growth of social media and the trend toward joint efforts of large organizations in the last decade, provided new opportunities to achieve the League's mission. Some examples follow.

2.1 | The new era of media and communications

The offices of Web, Media, and Communications were established. Substantial League resources are now devoted to state of the art, efficient web portals, and to the creation and dissemination of relevant content for all key activities of the League and its Regional Boards [www.ilae.org]. This

Number of Visits

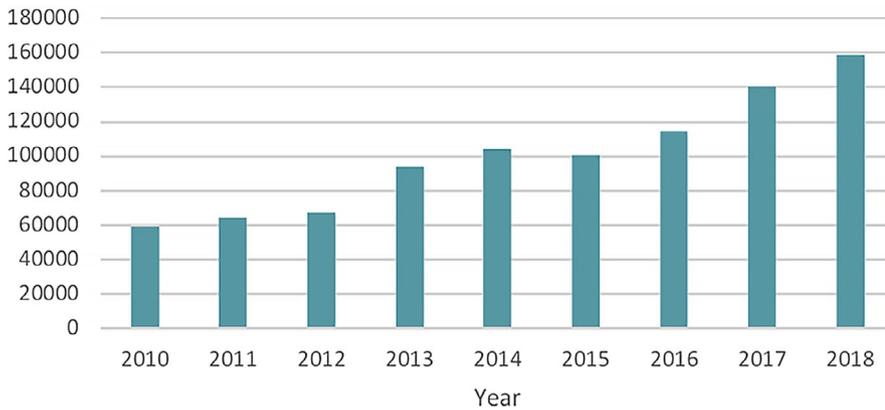


FIGURE 1 Visits to the ILAE web page have tripled in the last decade

Real Time Hits is a report of the total pageviews on your article. Each "hit" equals a click to view your article.

Lib	Date	Title	Total to Date
November 2018			
Med	13-Nov	Alzheimer's disease and epilepsy: Unraveling the Connections	3581
Med			
October 2018			
Med	24-Oct	Time is Brain: Treating Status Epilepticus	5472
Med	24-Oct	Epilepsy in the emergency department: Too much neuroimaging?	5431
Med	10-Oct	Does Caffeine Increase Risk for Seizures?	7411
Med	10-Oct	Neonatal seizures: Closing the knowledge and treatment gap	4335
Med	03-Oct	Overcoming the stigma of epilepsy in Asia: Cues from Confucius?	5821
September 2018			
Med	04-Sep	One-Day Pediatric Epilepsy Training Becomes Worldwide Movement	7193
Med	04-Sep	Proof of Concept Study Aims for Rapid Genotyping to Guide Epilepsy...	5886
August 2018			
Med	07-Aug	Meet the New Drug, Same as the Old Drug: Influx of New Epilepsy Medications...	3471
Med	07-Aug	Cannabis for Epilepsy? Debate Addresses Opinions on Medical Marijuana for...	4839

FIGURE 2 Sample of total pageviews through Newswire/Medwire of several of the League's articles

has resulted in a steady increase in the use of the ILAE website, with three times more visitors in 2018 compared to 2010 (Figure 1). In the last decade, the League is also using new media to deliver targeted messages to clinicians, patients, and stakeholders. For example, communication is delivered through YouTube channels [<https://www.youtube.com/watch?v=akMvNIXMHKc>], via podcasts [<https://www.ilae.org/journals/epigraph/epigraph-vol-21-issue-1-winter-2019/raphael-mechoulam-and-the-history-of-cannabis-research>], and through news-style publications. ILAE news articles are increasingly picked up by news agencies and media outlets (Figure 2), thus engaging an international audience, and helping disseminate relevant and accurate information about epilepsy worldwide.

2.2 | Joining forces for a global agenda

Collaboration with influential regional and international organizations continues to grow, as do the League's efforts to reach out to different demographics. Examples of collaborations include joint educational activities with the World Federation of Neurology (WFN) globally, and with the International Brain Research Organization (IBRO) in Africa; partnerships in education and guideline creation with the

International Federation of Clinical Neurophysiology; guideline creation with the European Academy of Neurology; international lobbying for epilepsy research involving the National Institutes for Neurological Disorders and Stroke (NINDS), the European Commission and a number of national health organizations; and the all-important collaboration with the World Health Organization (WHO) and its Regional Health Agencies such as the Pan American Health Organization (PAHO).

Examples of initiatives where the League played an important role include the Written Declaration of Epilepsy passed by the European Parliament in 2011,^{1,2} the finalization of the PAHO Strategy and Plan of Action on Epilepsy for the Americas,³ and the production of the epilepsy report by the US Institute of Medicine.⁴

Despite the success of these initiatives, there was a clear need to raise the visibility of epilepsy and to trigger actions on a planetary scale. As early as 2013, the ILAE, its sister lay organization, the International Bureau for Epilepsy (IBE), and their many chapters and members started to sensitize national governments to the importance of bringing the unmet needs of epilepsy to the attention of the World Health Assembly (WHA). The tremendous efforts and the roadmap to ensure the success of this initiative are published in

TABLE 1 Resolution on Epilepsy 68.2 adopted on May 26, 2015 by the 68th World Health Assembly. List of key actions recommended to Member States

- Strengthen effective leadership and governance, for policies on general health, mental health, and noncommunicable diseases that include consideration of the specific needs of people with epilepsy, and make the financial, human and other resources available that have been identified, as necessary, to implement evidence-based plans and actions;
- Introduce and implement, where necessary and in accordance with international human rights norms and standards, national healthcare plans of action for epilepsy management, aiming to overcome inequalities and inequities in health, social, and other related services, paying special attention to people with epilepsy living in conditions of vulnerability, such as those living in poor and remote areas, including by strengthening public health-care services, and training local human resources with proper techniques;
- Integrate epilepsy management, including health and social care, particularly community-based services, within the context of universal health coverage, including community-based rehabilitation, into primary health care, where appropriate, in order to help to reduce the epilepsy treatment gap, by training non-specialist health care providers to provide them with basic knowledge for the management of epilepsy so that epilepsy can be diagnosed, treated and followed up as much as possible in primary health care settings, as well as by empowering people with epilepsy and their carers for greater use of specified self and home care programs, by ensuring a strong and functional referral system and by strengthening health information and surveillance systems to routinely collect, report, analyze, and evaluate trends on epilepsy management;
- Support the establishment and implementation of strategies for the management of epilepsy, particularly to improve accessibility to and promote affordability of safe, effective, and quality-assured antiepileptic medicines and include essential antiepileptic medicines into national lists of essential medicines;
- Ensure public awareness of and education about epilepsy, in particular in primary and secondary schools, in order to help to reduce the misconceptions, stigmatization, and discrimination regarding people with epilepsy and their families that are widespread in many countries and regions;
- Promote actions to prevent causes of epilepsy, using evidence-based interventions, within the health sector and in other sectors outside health;
- Improve investment in epilepsy research and increase research capacity;
- Engage with civil society and other partners in the actions referred to above

Epilepsia.⁵ On May 26, 2015, delegates of the WAH from 42 countries and five continents stood up and made strong statements in support of the Resolution on Epilepsy [<https://www.ibe-epilepsy.org/wp-content/uploads/2015/05/NewResolutionText.pdf>] (Table 1). This resulted in unanimous approval of Resolution WHA 68.20, by all 194 Member States at the Health Assembly, in a truly historic moment [www.who.int/

[mental_health/neurology/epilepsy/resolution_68_20/en/](http://www.who.int/mental_health/neurology/epilepsy/resolution_68_20/en/)]. Concrete follow-up actions stemming from the Resolution are taking place in several countries, often in consultation with ILAE and IBE national constituencies. Most recently, ILAE and IBE in collaboration with the WHO are producing a Global Report on Epilepsy, to be launched at the International Epilepsy Congress in Bangkok in 2019. Hopefully, the Report will result in the preparation and approval of a Global Action Plan on Epilepsy by the WHA.

2.3 | Standing up for epilepsy

The League recognizes the urgency to reach out to the public and to policymakers to increase knowledge of and support for epilepsy, and to eliminate the life-destroying stigma experienced by people with epilepsy. In collaboration with the IBE the ILAE has taken steps in that direction in the last 10 years. For example, during a recent European football championship for players under 21 years in Sweden, teams of athletes with epilepsy from across Europe played a match just before the European Championship semi-finals kick off. The teams included several top-level former professional footballers, who generously agreed to participate. Through considerable lobbying, the task force on Sports and Epilepsy subsequently created a collection of photographs of famous athletes interacting with people with epilepsy [www.ilae.org/about-ilae/public-policy-and-advocacy/epilepsy-and-sport-project-stand-up-for-epilepsy]. This collection of images was launched at the London European Epilepsy Congress in 2012 in the ExCel Arena, the largest of the 2012 Olympic venues. The photographs convey the message that people with epilepsy, like athletes themselves, can be inspired to achieve their goals and lead full and active lives (Figure 3). To raise awareness about epilepsy, ILAE and IBE also launched in 2015 the International Epilepsy Day, which since then is celebrated annually across the world on the second Monday of February.⁶

3 | EDUCATION AT THE CORE

Lack of education is one of the main barriers to epilepsy care worldwide. Education has long been a core activity of the League and in the last decade, the League's educational initiatives reached a new level of maturity. The organizational and financial stability of the Virtual Epilepsy Academy (VIREPA) was solidified and continues to be one of the prime educational offerings. The International and Regional Congresses are being re-structured to meet the educational needs of the League's vast constituency and to promote translational research with better communication between basic scientists and clinicians. The League has increased financial support for courses through its Regional Commissions;

placed on the web for public comments, and re-reviewed based on feedback by an ad hoc Task Force, prior to final approval as an ILAE position statement. This procedure ensures that the League's position papers reflect not only knowledge of a selected group of experts, but also the input of the entire international constituency. The first position paper approved through this process was the practical (operational) clinical definition of epilepsy, published in 2014.¹⁰ This was followed in March 2017 by the final position papers on the classification of epileptic seizures,¹¹ and of epilepsies.¹² In addition to these position papers, the League's commissions and task forces have produced a large number of consensus reports on topics such as cortical dysplasias, hippocampal sclerosis, status epilepticus, and neonatal seizures and are currently producing consensus definitions of epilepsy syndromes. A related initiative aimed at improving diagnosis of seizure types and epilepsy syndromes is the cutting edge online diagnostic manual of the epilepsies, *epilepsydiagnosis.org* [www.epilepsydiagnosis.org], developed in partnership with eResearch at the University of Melbourne, launched formally in September 2014 and revised in 2018. The manual presents a large amount of information now available on the epilepsies and their etiologies, including clinical features, genetics, and videos, in a manner that is concise, current, and accessible to a global audience. Translation of the manual into several languages is ongoing.

The League is privileged to engage top epilepsy experts in the world to work on various Commissions and Task forces which produce a wide range of reports and publications in epilepsy. This led to the realization that a methodologically sound and systematic approach was necessary for the creation of guidelines and recommendations. After an extensive assessment of various guideline processes used by large health organizations around the world, the League adopted and published a guiding manual and toolbox for the creation of guidelines, and recommendations for consensus statements.¹³ The League now supports dedicated methodological expertise for this purpose.

4.2 | The League's Journals – A growing family

Another major advance during the last ten years was a significant expansion of the League's publication portfolio. *Epilepsia*, the League's historical flagship journal, was joined in 2013 by *Epileptic Disorders*, which was acquired by ILAE for the specific goal of acting as vehicle for educational content. The next step was the launch in 2016 of *Epilepsia Open* in a response to a call from our community, which believed that the League's existing publication portfolio was insufficient to host the ever-increasing amount of high-quality epilepsy research conducted throughout the world, and the demand for open access to high quality content. By publishing in

an open access journal, authors can ensure that their research is readily accessible to the entire scientific community and to lay people without any subscription fee. Finally, in 2017 the League engaged in an entirely novel endeavour involving publications in Wikipedia. Because Wikipedia is one of the most widely used resources for clinical questions around the world, the League saw an opportunity for wide dissemination of accurate information about epilepsy through this medium and created the *Wikipedia Initiative*, with an editorial team and a growing number of writers. The aim is to link forces with other Wikipedians in order to edit and create epilepsy entries and to link to open access publications. The first Wikipedia hands-on workshop for epilepsy writers will be held at the 33rd International Epilepsy Congress in Bangkok.

4.3 | Tackling the bench to bedside research gap

To optimize and accelerate translation of preclinical epilepsy research findings to the clinics, the ILAE created in 2010 a working group to formulate recommendations for preclinical epilepsy drug discovery. In 2012, a joint ILAE and American Epilepsy Society (AES) international translational epilepsy research workshop set a roadmap for translational initiatives and research priorities. Subsequently, a joint ILAE/AES translational task force which includes hundreds of volunteer epilepsy experts worldwide has been working on the following aims: (a) propose practice standards and create online resources for the harmonization of preclinical video-electroencephalography studies, (b) perform systematic reviews of preclinical studies utilizing seizure models, (c) create preclinical common data elements (CDEs) to optimize preclinical research reporting, utilization of big databases, and and collaborations across laboratories, and (d) propose methodology and infrastructure to allow multicenter preclinical studies.

5 | THE NEXT GENERATION

Engaging the younger generations of epilepsy professionals in the League in a meaningful way has been a central aim in recent years. In 2017, the "Next Generation" Task Force was created to support three important initiatives:

5.1 | The YES initiative

In 2018, the YES (Young Epilepsy Section), a dynamic and effective group of professionals under 40 was formally organized. Its aims are to improve the professional development of young professionals in epilepsy, and to deepen the participation of young people in the ILAE. YES members are currently active in all regions of the world. They are involved in translation, creation of educational materials,



FIGURE 4 The Young Epilepsy Section (YES) was founded in 2018 to engage the next generations of epilepsy professionals in Epilepsy

publications, and Wikipedia entries, and they also form part of the Scientific Organizing Committee of the League's congresses [www.ilae.org/about-ilae/topical-commissions/young-epilepsy-section-yes] (Figure 4).

5.2 | Mentors and mentees

Starting in 2017, a mentor-mentee program takes place at ILAE congresses and provides an opportunity for interaction between individuals in the early stages of their careers and seasoned epilepsy professionals, with the aim of sharing experiences that can inform the careers of the next generation of epileptologists.

5.3 | The leadership development program

This highly successful, intensive program is aimed at individuals in their early-mid career who are taking on leadership roles in their own region. It takes place over 2 days at the League's International Congresses and is now being deployed in Regional Congresses.

6 | ENSURING ORGANIZATIONAL AND FINANCIAL VIABILITY

To enhance the management of the League's financial resources and to improve transparency in reporting and disclosing financial data, a Finance Committee and a Financial Advisory Subcommittee were instituted in 2009. These committees are in charge of monitoring the performance of the ILAE's investment portfolio and advising on investments. Both include senior professionals in the corporate environment who generously volunteer to provide the League with regular financial advice. Also, a new system for budgetary applications from the ILAE Commissions and Task Forces, and an annual Budget Review Committee were created to guide the allocation of the League's resources. One of the most important financial decisions in the last decade was the creation of an endowment that would provide steady financial

support for the League's activities through return on investments, thereby compensating for a decline in revenue from congresses and other sources. The endowment target of US \$ 20 million was reached in early 2019, and the League's financial advisors are designing a spending policy to support the League's projects, in accordance with its intended purpose.

ACKNOWLEDGMENTS

Throughout this report, the names of people responsible for the progress made in the last decade have been omitted. The efforts are multitudinous, and the League is truly fortunate to have such a dedicated group of colleagues and friends working toward a common goal. To all who have devoted their wisdom, time, and energy to the cause of epilepsy over the course of the last decade, and therefore to the 110th anniversary celebration of the League, we express deepest gratitude and appreciation.

CONFLICT OF INTEREST

EP received speaker's or consultancy fees from Amicus Therapeutics, Biogen, Eisai, GW Pharma, Sanofi, Sun Pharma, Takeda, UCB Pharma, and Xenon Pharma. SW received unrestricted educational grants from UCB Pharma and Eisai. SM is the Charles Frost Chair in Neurosurgery and Neurology and partially funded by grants from NIH U54 NS100064 and NS43209, US Department of Defense (W81XWH-13-1-0180) and the Heffer Family and the Segal Family Foundations and the Abbe Goldstein/Joshua Lurie and Laurie Marsh/Dan Levitz families. He serves as Associate Editor of Neurobiology of Disease and is on the editorial board of Brain and Development, Pediatric Neurology and Physiological Research. He receives from Elsevier an annual compensation for his work as Associate Editor in Neurobiology of Disease and royalties from 2 books he co-edited. He received a consultant fee from Mallinkrodt and UCB. He has no conflicts of interest in regards to this article. We confirm that we have read the Journal's position on issues involved in ethical publication and affirm that this report is consistent with those guidelines.

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