President’s Report

Emilio Perucca

Barcelona, Chapters Convention, 2 September 2017
Tackling the Global Burden of Epilepsy: Key Challenges

• Improve access to diagnosis and treatment

• Improve awareness and fight stigma, prejudice and discrimination

• Improve epilepsy knowledge in professionals and allied health practitioners

• Nurture the leaders of tomorrow

• Foster development of innovative and more efficacious treatments
ILAE 2013-2017- Some Achievements

• 39 publications from ILAE Commissions / Task Forces approved in the current term

• Expanded educational programme, including Virepa, and Epilepsy in Wikipedia

• Launch of Epilepsia Open

• Improved organizational structure and governance

• Advocacy achievements – WHA Resolution, International Epilepsy Day, Global Research Priorities Initiative
ILAE classification of the epilepsies: Position paper of the ILAE Commission for Classification and Terminology

1,2,3Ingrid E. Scheffer, 1Samuel Berkovic, 4Giuseppe Capovilla, 5Mary B. Connolly, 6Jacqueline French, 7Laura Guilhoto, 8,9Edouard Hirsch, 10Satish Jain, 11Gary W. Mather, 12Solomon L. Moshé, 13Douglas R. Nordli, 14Emilio Perucca, 15Torbjörn Tomson, 16Samuel Wiebe, 17Yue-Hua Zhang, and 18,19Sameer M. Zuberi

Epilepsia, 58(4):512–521, 2017
doi: 10.1111/epi.13709

Operational classification of seizure types by the International League Against Epilepsy: Position Paper of the ILAE Commission for Classification and Terminology

*Robert S. Fisher, †J. Helen Cross, ‡Jacqueline A. French, §Norimichi Higurashi, ¶Edouard Hirsch, #Floor E. Jansen, **Lieven Lagae, ††Solomon L. Moshé, †††Jukka Peltola, §§Eliane Roulet Perez, ¶¶Ingrid E. Scheffer, and ####Sameer M. Zuberi

Epilepsia, 58(4):522–530, 2017
doi: 10.1111/epi.13670
A new classification is born

Co-chairs: Emilio Perucca (Italy) & Athanasios Covannis (Greece)

Developing a classification of seizures and epilepsy: Lessons from history
Solomon L. Moshé- (USA)

The ILAE classification of seizures
Sameer Zuberi (United Kingdom)

The ILAE classification of the epilepsies
Ingrid Scheffer (Australia)

The new classification: cultural context and implications for people with epilepsy
Satish Jain (India)
EpilepsyDiagnosis.org

The ILAE Commission on Classification and Terminology welcomes you to EpilepsyDiagnosis.org, a cutting-edge online diagnostic manual of the epilepsies.

Goal

The goal of epilepsydiagnosis.org is to make available, in an easy-to-understand form, the latest concepts relating to seizures and the epilepsies. The principle goal is to assist clinicians who look after people with epilepsy anywhere in the world to diagnose seizure type(s), classify epilepsy, diagnose epilepsy syndromes, and define the etiology of the epilepsy. The site is principally designed for clinicians in primary and secondary care settings caring for people with epilepsy and we hope will also serve as a useful teaching aid.

Structure

The structure of this site reflects the importance of seizure type, syndrome, and etiology in clinical practice. On this website, you will find current classification concepts for seizures, with their clinical features, video examples, EEG correlates, differential diagnosis and related epilepsy syndromes. Epilepsy syndromes are detailed by their clinical features, seizure types, EEG, imaging and genetic correlates and differential diagnoses. The site includes sections on etiologies of epilepsies and epilepsy imitators with cross-referencing between these sections and seizure and syndrome sections.

Definition of epilepsy

Epilepsy is a disease of the brain defined by any of the following conditions:

- At least two unprovoked (or reflex) seizures occurring more than 24 hours apart
The current state of epilepsy guidelines: A systematic review

*†Khara M. Sauro, *†Samuel Wiebe, ‡Colin Dunkley, §Jozsef Janszky, ¶Eva Kumlien, **Solomon Moshé, ††Nobukazu Nakasato, ‡‡Timothy A. Pedley, §§Emilio Perucca, ††¶Horacio Senties, ***Sanjeev V. Thomas, †††Yuping Wang, †††¶Jo Wilmshurst, and *†Nathalie Jetté

doi: 10.1111/epi.13273

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Developing clinical practice guidelines for epilepsy: A report from the ILAE Epilepsy Guidelines Working Group

*†Khara M. Sauro, *‡Samuel Wiebe, ‡Emilio Perucca, §Jacqueline French, ‡Colin Dunkley, #Alejandro de Marinis, **Martin Kirkpatrick, and *†Nathalie Jetté

Epilepsia, 56(12):1859–1869, 2015
doi: 10.1111/epi.13217
The Information Revolution: The Empowered Patient
ILAE and Epilepsy in Wikipedia

Most frequently consulted sites for information about epilepsy (ranking order):

- Google #1
- Wikipedia #5
- Pubmed #179
- Medscape #2,196
- ILAE #498,000
- AES #750,000

Facts and figures about Wikipedia:

- 43 million articles
- 410 million medical page views/month
- 285 languages
- 85,345 views on epilepsy in the last 30 days
- 300 million Wikipedia zero people who can access freely with their mobile phones

Search term ‘epilepsy’

- 31,500,000
- 168,073

Courtesy of Sam Wiebe (modified)
## Improving Services to Our Younger Members: Registration Fees (EUR) for IECs – 2011 to 2017

<table>
<thead>
<tr>
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<th>2011 (Rome)</th>
<th>2013 (Montreal)</th>
<th>2015 (Istanbul)</th>
<th>2017 (Barcelona)</th>
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<td><strong>Regular</strong></td>
<td>655</td>
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<tr>
<td>**Junior ***</td>
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<td>**Jr Member ***</td>
<td>500</td>
<td>365</td>
<td>300</td>
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*under 40 years of age
Number of Registered Delegates at IECs

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<th>Year</th>
<th>City</th>
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<td>2003</td>
<td>Lisbon</td>
<td>3518</td>
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<tr>
<td>2005</td>
<td>Paris</td>
<td>5090</td>
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<td>2007</td>
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<td>2009</td>
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<td>2013</td>
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<td>2334</td>
</tr>
<tr>
<td>2015</td>
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<td>2500</td>
</tr>
<tr>
<td>2017</td>
<td>Barcelona</td>
<td>&gt;3000</td>
</tr>
</tbody>
</table>
2017 Lifetime Achievement Award

Social Accomplishment Award
What Does ILAE Do for Tomorrow’s Leaders?

• A rich program of courses and summer schools, with extensive bursary support

• Training fellowships

• Mentorship initiatives, e.g. through participation in Commission and Task Forces

• Recognition programs, e.g. prizes for excellence in publications and many other awards

• Facilitated access to Regional and International Congresses
Epilepsia 2017 Basic Science Prize

Sarah Weckhuysen
Epilepsia 2017 Clinical Research Prize

Hiroko Ikeda
Epileptic Disorders 2017 Educational Prize
Global burden of epilepsy and the need for coordinated action at the country level to address its health, social and public knowledge implications.
From global campaign to global commitment: The World Health Assembly’s Resolution on epilepsy

*Athanasiou Kovannis, †Alla Guekht, ‡Shichuo Li, §Mary Secco, ¶Raad Shakir, and **Emilio Perucca

doi: 10.1111/epi.13192
Salud crea Unidad de Trabajo Intersectorial para el control de la epilepsia

Martes, 10 de Noviembre de 2015 13:01
Improving Access to Newer Treatments

- An ILAE Regulatory Task Force has been established which communicates constructively with regulatory agencies.
- Several meetings organized with representatives from FDA, EMA and PMDA.
- Goals include facilitating access of safe and effective treatments – issues addressed include monotherapy use, pediatric indications, and drugs for status epilepticus.
Development of new treatment approaches for epilepsy: Unmet needs and opportunities

*Jacqueline A. French, †H. Steve White, ‡Henrik Klitgaard, §Gregory L. Holmes, ¶Michael D. Privitera, **Andrew J. Cole, ††Ellinor Quay, †††Samuel Wiebe, §§Dieter Schmidt, ¶¶¶Roger J. Porter, ††††Alexis Arzimanoglou, †††††Eugen Trinka, and §§§Emilio Perucca
Estimated NIH and Private per Patient Funding for Research by Disease

USD/patient

$700

$600

$500

$400

$300

$200

$100

$0

Epilepsy

$603

Parkinson’s

$464

Autism

$189

Alzheimer’s

Per patient estimates based on prevalence numbers in the IOM report of 2012. Research dollars include 2011 NIH and private funding only.

Stand Up for Epilepsy!
COMMENTARY: WHY AN INTERNATIONAL EPILEPSY DAY?

Emilio Perucca, ILAE
President, C. Mondino National Neurological Institute and Department of Internal Medicine and Therapeutics, University of Pavia, Pavia, Italy.

doi: 10.1111/epi.12813

Epilepsy entails a huge burden not only for its epidemiologic dimension (close to 1% of the world’s population) but also for its impact on quality of life of affected individuals, particularly those whose seizures are not fully controlled. In the recent Global Burden of Disease Study, severe epilepsy ranked fourth in terms of disability weight among 220 health states surveyed.\textsuperscript{1} Despite the fact that epilepsy is the only chronic serious neurologic disease that can be successfully treated with inexpensive medications,\textsuperscript{2} epilepsy is associated with staggering unmet needs. The majority of people with epilepsy around the world do not have regular access to antiseizure medications, and overall quality of epilepsy care is suboptimal, even in the most affluent nations.\textsuperscript{3,4} In addition, removing barriers to high-quality care does not ensure therapeutic success. About one third of people with epilepsy are treatment resistant, and research efforts need to be stepped up to better understand pathophysiologic mechanisms and to develop more effective therapies.\textsuperscript{5} Gaps in medical care are not the only priorities to be addressed. Everywhere on the planet, the lives of people with epilepsy are adversely affected by stigma, prejudice, and discrimination, which are due in large part to lack of public knowledge about the nature of the disease.\textsuperscript{6} For the same reasons, in many countries people with epi-
SPECIAL REPORT

Epilepsy priorities in Europe: A report of the ILAE-IBE Epilepsy Advocacy Europe Task Force

*Michel Baulac, †Hanneke de Boer, ‡Christian Elger, §Mike Glynn, ¶Reetta Kälviäinen, **Ann Little, ††Janet Mifsud, ‡‡Emilio Perucca, §§Asla Pitkänen, and ¶¶Philippe Ryvlin

doi: 10.1111/epi.13201

SPECIAL REPORT

Research priorities in epilepsy for the Asia-Oceanian region

*Patrick Kwan, †Leonor Cabral-Lim, ‡Wendyl D’Souza, §Satish Jain, ¶Byung-In Lee, #Weiping Liao, **Shih-Hui Lim, ††Taisuke Otsuki, ‡‡Chong-Tin Tan, and §§Masako Wantanabe, for the CAOA Research Task Force

doi: 10.1111/epi.12957
TOWARDS A GLOBAL ALLIANCE ON EPILEPSY RESEARCH

Workshop organised by Epilepsy Alliance Europe and hosted by Brian Hayes, MEP and members of the European Advocates for Epilepsy Group

European Parliament, 7 February 2017

Making epilepsy a global healthcare priority
The ILAE Team: 2013-2017

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Jane Hegarty

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Finola Quinn

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Kathryn Hodgson

Philippa Scott

Alma Paez Lynch

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