

# 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**

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

# Presidential Symposium

## Congress Hall

09:30 – 11:30

### **A new classification is born**

*Co-chairs: Emilio Perucca (Italy) & Athanasios Covanis (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)

# <https://www.epilepsydiagnosis.org>



> Overview

Log In For Videos

Overview

Log In for Videos

Give Feedback

Seizure Classification

Generalized seizures ▶

Focal seizures ▶

Focal/Generalized ▶

Epilepsy syndromes

Neonatal/Infantile ▶

Childhood ▶

Adolescent/Adult ▶

Variable Age ▶

Epilepsies by Etiology

Genetic ▶

Structural ▶

Metabolic ▶

Immune ▶

Infectious ▶

Unknown ▶

## 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, 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 correlate, 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

## FULL-LENGTH ORIGINAL RESEARCH



# 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

*Epilepsia*, 57(1):13–23, 2016  
doi: 10.1111/epi.13273

---

## SPECIAL REPORT

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

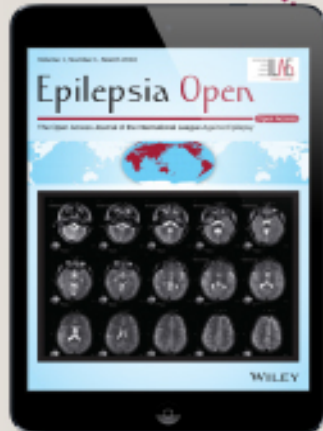
\*†Khara M. Sauro, \*†Samuel Wiebe, ‡Emilio Perucca, §Jacqueline French, ¶Colin Dunkley, #Alejandro de Marinis, \*\*Martin Kirkpatrick, and \*†Nathalie Jetté

*Epilepsia*, 56(12):1859–1869, 2015  
doi: 10.1111/epi.13217



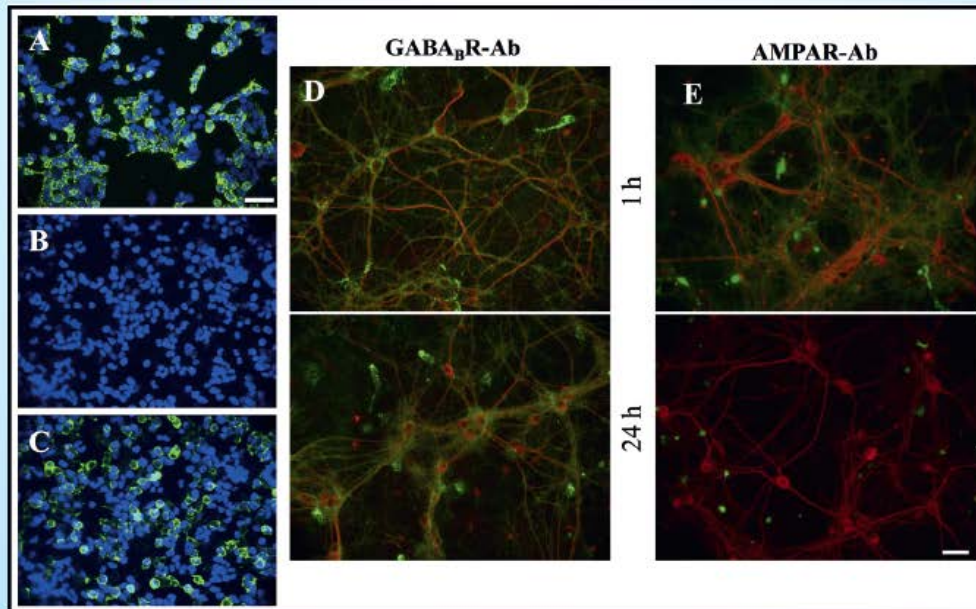
Epilepsia *Open*® The Open Access Journal of  
the International League Against Epilepsy

Open Access



The latest issue is  
available now  
All articles are  
open access

Read  
for free!

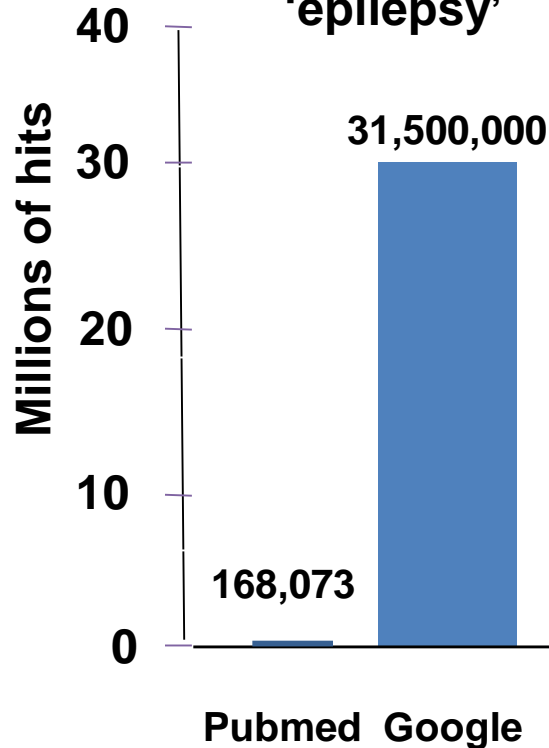




# The Information Revolution: The Empowered Patient

## ILAE and Epilepsy in Wikipedia

Search term  
'epilepsy'



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

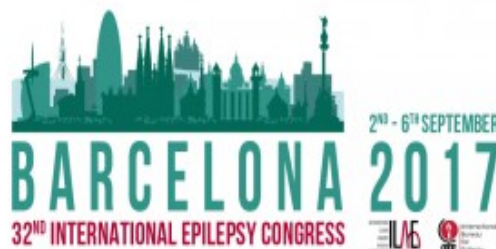
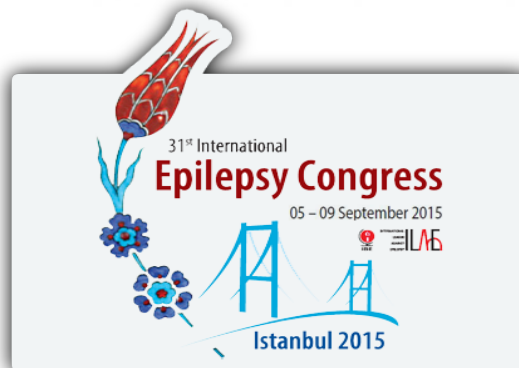
Google	# 1
Wikipedia	# 5
Pubmed	# 179
Medscape	# 2,196
ILAE	# 498,000
AES	# 750,000



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



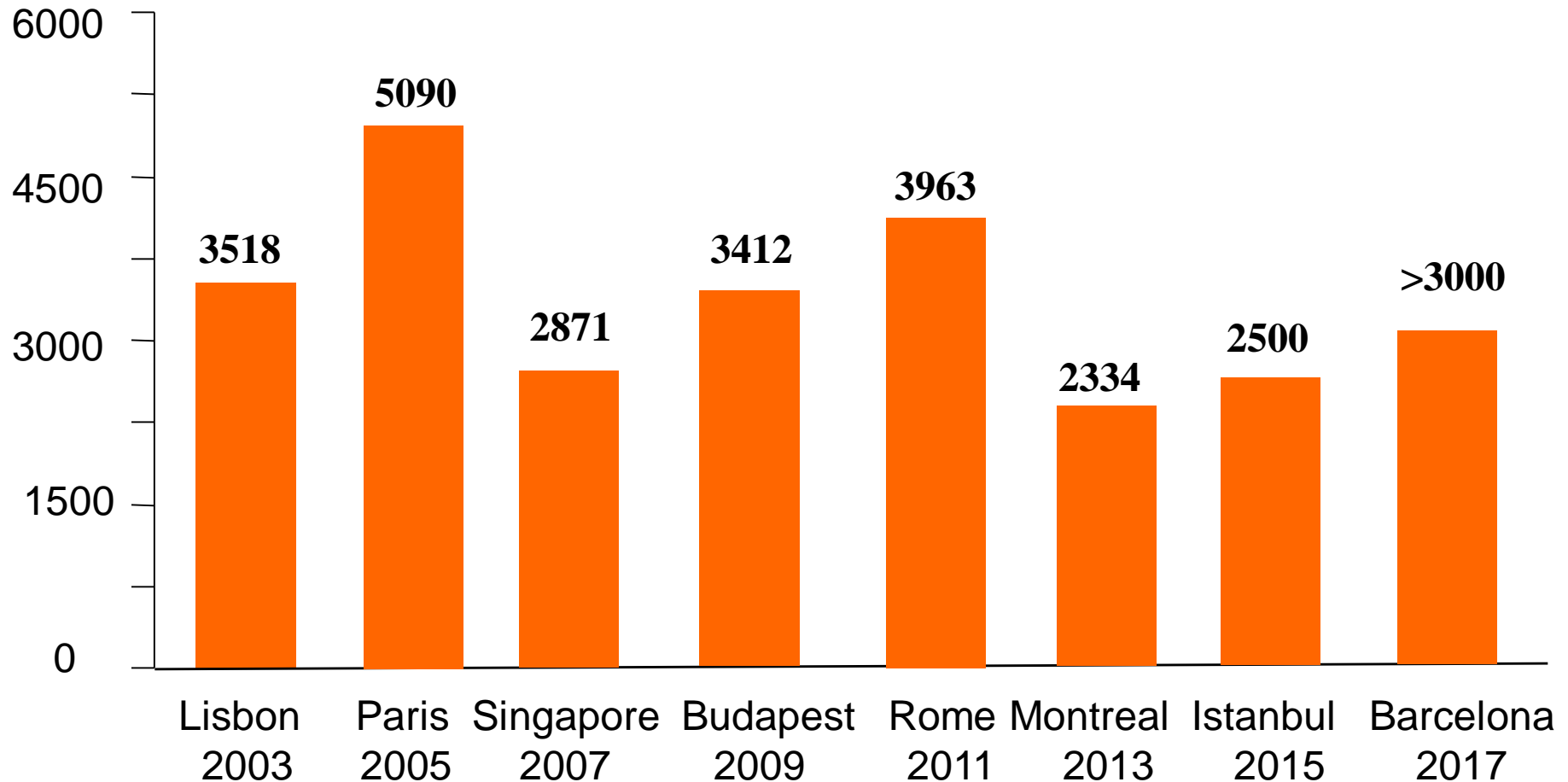


# Improving Services to Our Younger Members: Registration Fees (EUR) for IECs – 2011 to 2017

	2011 (Rome)	2013 (Montreal)	2015 (Istanbul)	2017 (Barcelona)
<i>Regular</i>	655	545	545	615
<i>Chapter Members</i>	<b>655</b>	<b>495</b>	<b>400</b>	<b>430</b>
<i>Junior *</i>	500	415	365	400
<i>Jr Member*</i>	<b>500</b>	<b>365</b>	<b>300</b>	<b>325</b>

\*under 40 years of age

# Number of Registered Delegates at IECs





*Charlotte Dravet*

2017 Lifetime Achievement  
Award



*Susan Axelrod*

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







*Tiwalade Sobayo*

Epilepsia  
2017 Basic Science Prize



*Sarah Weckhuysen*

Epilepsia  
2017 Clinical Research Prize



*Hiroko Ikeda*

Epileptic Disorders  
2017 Educational Prize





World Health  
Organization

## **Approval of the Epilepsy Resolution by the World Health Assembly: A Historical Landmark | Tuesday 26th May 2015**

**Global burden of epilepsy and the need for  
coordinated action at the country level to address its  
health, social and public knowledge implications**

## COMMENTARY: THE WORLD HEALTH ASSEMBLY'S RESOLUTION ON EPILEPSY



Athanasios Covanis,  
President, International  
Bureau for Epilepsy



Emilio Perucca, President,  
International League Against  
Epilepsy

# From global campaign to global commitment: The World Health Assembly's Resolution on epilepsy

**\*Athanasios Covanis, †Alla Guekht, ‡Shichuo Li, §Mary Secco, ¶Raad Shakir, and  
\*\*Emilio Perucca**

*Epilepsia*, 56(11):1651–1657, 2015  
doi: 10.1111/epi.13192

---

Con la participación de sociedades científicas

## Salud crea Unidad de Trabajo Intersectorial para el control de la epilepsia

Martes, 10 de Noviembre de 2015 13:01

### Radio Salud

#### Spots



Chagas: Una realidad que podemos cambiar



# 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



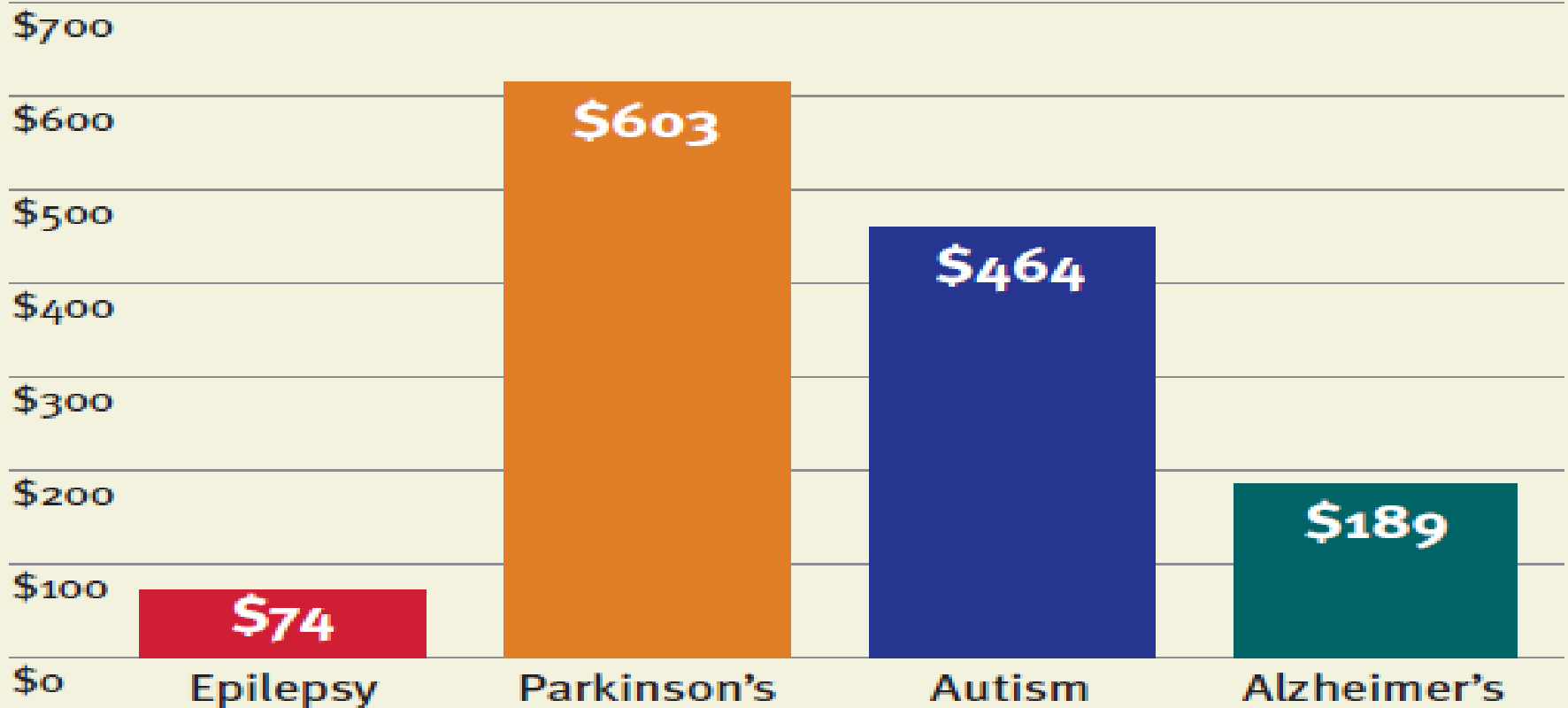
## PRECLINICAL THERAPY DISCOVERY

### 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

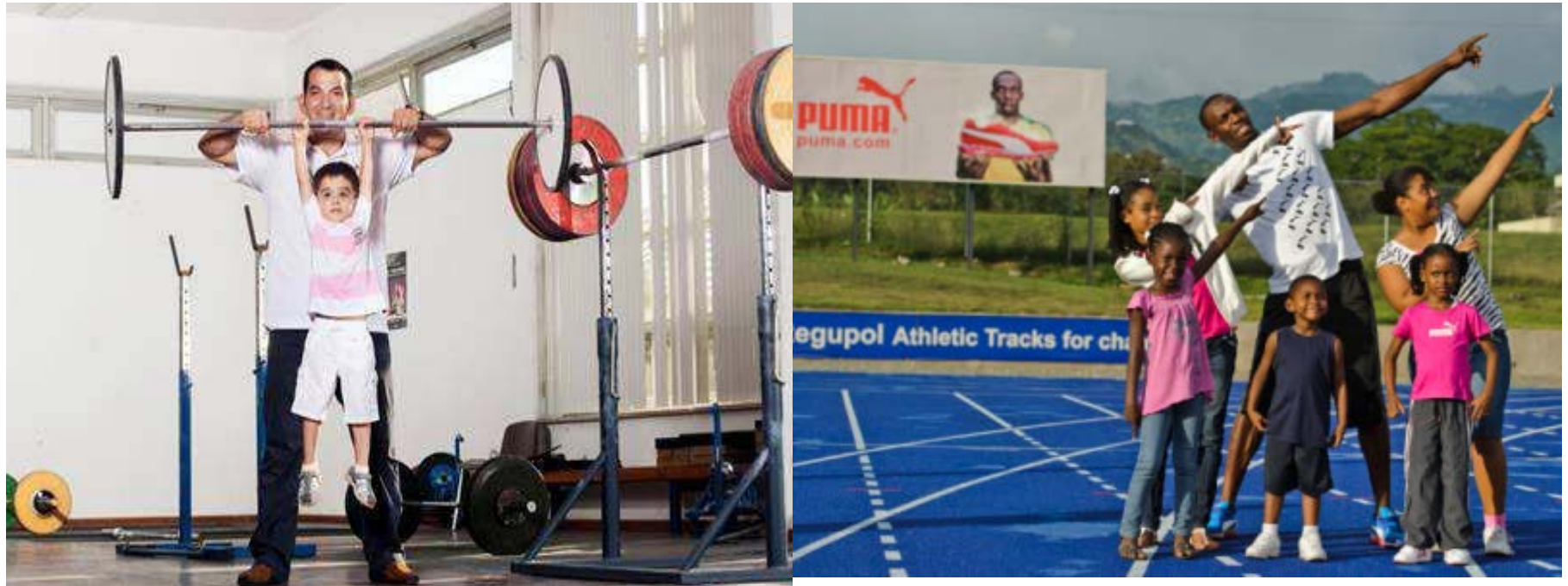
USD/patient



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.<sup>1</sup> Despite the fact that epilepsy is the only chronic serious neurologic disease that can be successfully treated with inexpensive medications,<sup>2</sup> 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.<sup>3,4</sup> 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.<sup>5</sup> 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.<sup>6</sup> 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

*Epilepsia*, 56(11):1687–1695, 2015  
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

*Epilepsia*, 56(5):667–673, 2015  
doi: 10.1111/epi.12957

---

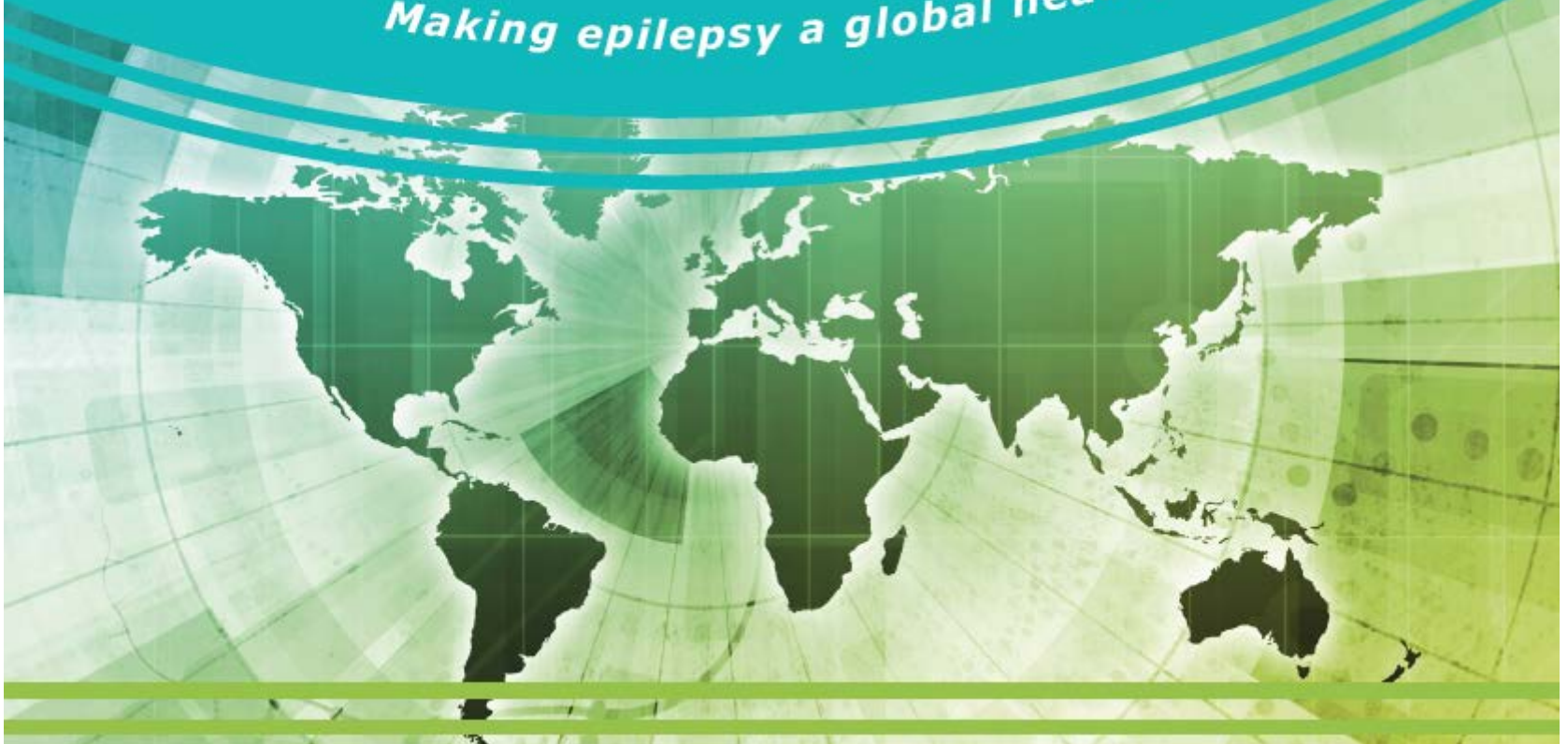


# TOWARDS A GLOBAL ALLIANCE ON EPILEPSY RESEARCH

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*









under the auspices of:



**World Health  
Organization**



EUROPEAN MEDICINES AGENCY  
SCIENCE MEDICINES HEALTH



# The Team - 2013-2017



**Emilio Perucca**  
**President**



**Tatsuya Tanaka**  
**Vice President**



**Sam Wiebe**  
**Treasurer**



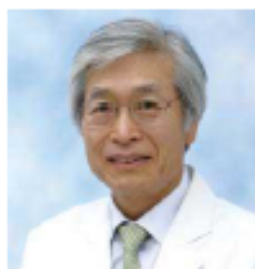
**Helen Cross**  
**Secretary General**



**Solomon Moshé**  
**Past President**



**A. Gallo Diop**  
**CAA**



**Byung-In Lee**  
**CAOA**



**Meir Bialer**  
**CEA**



**Hassan Hosny**  
**CEMA**



**Marco Medina**  
**CLAA**



**Sheryl Haut**  
**CNAA**



**Astrid Nehlig**  
**Epilepsia**  
**Editor-in-chief**



**Gary Mathern**  
**Epilepsia**  
**Editor-in-chief**



**Mike Sperling**  
**Epilepsia**  
**Editor-in-chief**



**Alexis Arzimanoglou**  
**Epileptic Disorders**  
**Editor-in-chief**



**Athanasios Covanis**  
**IBE President**



**Sari Tervonen**  
**IBE Secretary General**



**Robert Cole**  
**IBE Treasurer**



# The ILAE Team: 2013-2017



Priscilla Shisler  
Administrative Director



Donna Cunard  
Financial Manager



Richard Holmes



Gus Egan



Jane Hegarty



Kathryn Hodgson



Denis McEvoy



Gina Phelan



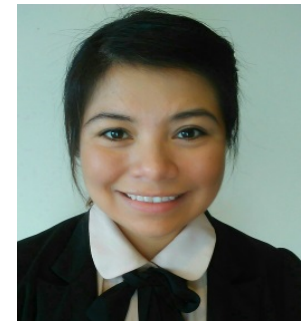
Philippa Scott



Helen Donohue



Finola Quinn



Alma Paez Lynch

# 2017 - 2021 ILAE Executive Committee Members



Samuel Wiebe  
President



Alla Guekht  
Vice President



Edward Bertram  
Secretary-General



Helen Cross  
Treasurer



Emilio Perucca  
Past President



Angelina Kakooza  
Commission on  
African Affairs



Akio Ikeda  
Commission on Asian  
and Oceanian Affairs



Chahnez Charfi Triki  
Commission on Eastern  
Mediterranean Affairs



Eugen Trinko  
Commission on  
European Affairs



Roberto Caraballo  
Commission on Latin  
American Affairs



Nathalie Jetté  
Commission on North  
American Affairs



Astrid Nehlig  
*Epilepsia*  
Editor-in-Chief



Michael Sperling  
*Epilepsia*  
Editor-in-Chief



Martin Brodie  
IBE President



Mary Secco  
IBE Secretary-General



Anthony Zimba  
IBE Treasurer