



International Epilepsy Day

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Launching International Epilepsy Day

65 MILLION people around the world live with epilepsy

International Epilepsy Day will launch around the world on Monday 9 February 2015. Organised by the **International Bureau for Epilepsy (IBE)** and the **International League Against Epilepsy (ILAE)**, International Epilepsy Day will provide the platform for people with epilepsy to share their experiences and stories with a global audience and thereby to build a stronger epilepsy community.

Developed in line with a strategy to advocate for appropriate legislation to guarantee human rights of people with epilepsy and to empower people with epilepsy to maximise their quality of life, International Epilepsy Day aims to highlight that:

- epilepsy still remains a hidden disease due to the stigma attached;
- it is treatable, yet 40% of people living with epilepsy in wealthier countries do not receive appropriate treatment. Over 70% of those living in low income countries cannot even access epilepsy medication regularly;
- lack of treatment imposes a huge financial burden on national health systems;
- research and legislation remain key issues in improving the quality of life of persons with epilepsy.

Around the world, IBE and ILAE associations are holding events to highlight issues of particular relevance at national or regional level, while, internationally a series of activities using the hashtag **#epilepsyday** will provide global outreach, uniting the voices of IBE and ILAE associations in the **more than 125 countries** in which the organisations are represented around the world:

- **#epilepsyday** on Facebook, Twitter and Instagram.
- **#epilepsyday** in photos: Around the world people with epilepsy will use smartphones to catch the mood of the day on **#epilepsyday** message cards in landmark locations. With membership stretching from New Zealand to the US, this will be a major activity!

epilepsy.org is a key repository for information on International Epilepsy Day.

In the European Parliament an exhibition tells the stories of people with epilepsy from around the world; official launch by Carlos Moedas, EU Commissioner for Research, Science and Innovation and hosted by Brian Hayes MEP, on 10 February.

Athanasios Covanis, IBE President, said "International Epilepsy Day is the opportunity to lend a global voice to people with epilepsy. These are our most powerful advocates, which can have devastating consequences, affecting all aspects of the lives of people with epilepsy. Some of their stories, showing bravery in the face of adversity, are showcased on epilepsy.org, and demonstrate clearly that epilepsy is much more than seizures."

Emilio Perucca, ILAE President, added "International Epilepsy Day is a major step forward in raising awareness and improving the lives of people with epilepsy throughout the world. Its establishment is synergic with the approval, on 2 February, of the first WHO resolution on epilepsy by the WHO Executive Board in Geneva. The resolution, a true milestone, calls for a coordinated action in all member States to improve epilepsy care, protect the civil rights of people with epilepsy and increase investment into epilepsy research".

Facts about Epilepsy

- Epilepsy is a collective term for a large group of diseases of the brain that are characterized by seizures.
- A seizure is like an internal electrical storm. It is the consequence of abnormal, excessive discharges of nerve cells.
- Seizures are symptoms of the disease, they are not the disease itself, yet it is the seizures and associated stigma, rather than the condition itself, which ruin the lives of people with epilepsy.
- Epilepsy is the most common serious brain disease and a global problem that recognizes no class distinction or global boundary, affecting all ages, races, social classes, and countries.
- It is estimated that 65 million people have epilepsy.
- 2.5 million new cases are diagnosed annually .
- In the developed world, 40% of people with epilepsy do not receive appropriate treatment. This figure rises to over 80% in developing nations.
- Epilepsy can kill. SUDEP (Sudden Unexpected Death in Epilepsy) is responsible for 33,000 deaths in Europe alone each year, of which 40% are preventable.
- With appropriate treatment, up to 70% of people with epilepsy become seizure-free.
- 30% of people with epilepsy will be drug resistant.



About the International Bureau for Epilepsy (IBE)

- **IBE** is an international umbrella organisation of national epilepsy associations, which was founded in Rome in 1961.
- **IBE** exists to improve the social condition and quality of life of people with epilepsy and those who care for them by increasing awareness, understanding and knowledge of epilepsy.
- **IBE** currently has a membership of 132 epilepsy associations, based in 98 countries worldwide.
- www.ibe-epilepsy.org



About the International League Against Epilepsy (ILAE)

- **ILAE** was founded in 1909 and is the world's preeminent association of Epileptologists, neurologists and other healthcare professionals working in the field of epilepsy.
- **ILAE** is working towards a world where no persons' life is limited by epilepsy by ensuring that health professionals; people with epilepsy and their care givers; governments and the public, have the educational and research resources essential to understanding, diagnosing and treating persons with epilepsy.
- **ILAE**, with a membership policy of one member association (chapter) per country, has 121 chapters.
- www.ilae.org

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See Annexe for contact information at country level.

Press Release Annexe: COUNTRY CONTACTS

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