



International Epilepsy Day



@IntEpilepsyDay epilepsy.org #epilepsyday



International Epilepsy Day

About the day

- A joint initiative of the International Bureau for Epilepsy (IBE) and the International League Against Epilepsy (ILAE)
- Launched in 2015 and celebrated annually on second Monday of February
- With IBE and ILAE national chapters in more than 120 countries worldwide, it's a powerful opportunity to highlight the problems faced by people with epilepsy, their families and carers

Objectives

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.



A look back: International Epilepsy Day 2015



HOME

ILAE AND IBE

SPONSORS

CONTACT

ABOUT THE DAY

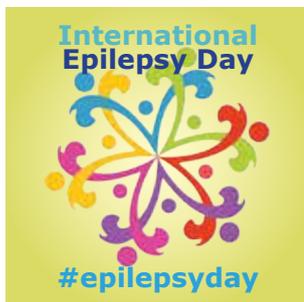
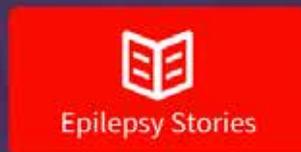
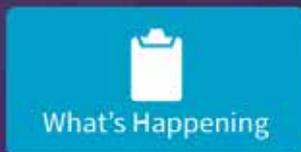
SELFIES

EPILEPSY STORIES

ABOUT EPILEPSY

WEBSITES BY COUNTRY

SOCIAL MEDIA AND DOWNLOADS



Clockwise from above:

- epilepsy.org: website dedicated to International Epilepsy Day
- One of the posters telling the personal stories of people with epilepsy that featured on the website and formed the week-long exhibition in the European Parliament
- Information postcards and posters
- Facebook badge



International Epilepsy Day



EMILIA SALMINEN Finland

Emilia's mother thanks epilepsy surgery

Epilepsy is more than Seizures

Five-year-old Emilia Salminen underwent extensive frontal-lobe surgery in the spring of 2014. The results have already surprised her parents and grandparents. Her epileptic seizures have stopped, and she is now more outgoing and self-confident. Her frequent nightmares are gone and her daily life is easier.

Emilia's operation was performed at Töölö Hospital in Helsinki. She was in surgery for eight hours. Mother, Tiina, put together a photo album for her daughter with pictures of all the preparatory procedures, the operation itself and her recovery time. Emilia happily looks at the album.

Emilia now goes to a specialised day care facility, and her mother can rest assured that she is receiving the best possible care and support from the expert, friendly personnel.

Tiina and Emilia have also taken part in a Finnish Epilepsy Association course for families. The best things about the course were peer support and learning how to approach and cope with issues. Tiina emphasizes the importance of her own attitude to Emilia's epilepsy.

Emilia's epileptic seizures were caused by a congenital developmental disorder of the frontal lobe. When the condition was at its worst, she suffered dozens of episodes a day. Medications did not seem to help. After exacting examinations, epilepsy surgery was decided as the best option. While Emilia no longer suffers from seizures, she continues to take epilepsy medication and her progress is carefully monitored.

International Epilepsy Day
9 February 2015

EPILEPSY is more than SEIZURES

You are in a public place
You see someone having a seizure
Would you know what to do?
Or, more important, what NOT to do?

#epilepsyday

EPILEPSY is more than SEIZURES

- Epilepsy is the most common serious disease of the brain affecting 65 million people around the world
- 2.5 million new cases are diagnosed each year
- 40% of people with epilepsy in the industrialised world do not receive appropriate treatment
- 80% of people with epilepsy in developing nations do not receive appropriate treatment
- With 30% of people with epilepsy being drug resistant research is critical to find treatments
- Epilepsy can cause death – SUDEP (Sudden Unexpected Death in Epilepsy)
- The many burdens and costs of epilepsy are often unrecognized because those afflicted with the disease strive it from the outside world to avoid discrimination
- Mortality rates of people with epilepsy are 2-3 times that of the general population
- For some people, the side effects of epilepsy can be more difficult to deal with than the epilepsy itself. Social problems include:
 - Cognitive impairment due to the disease or to medication leading to difficulties at school or, in some cases, exclusion from school
 - Employment problems: difficulty in finding employment and, irrespective of qualifications, employment can be low grade and low paid
 - Unfair driving regulations and insurance issues
 - Low self-esteem and high incidence of depression.

Help us to make a difference.
epilepsy.org



An initiative of the International League Against Epilepsy and International Bureau for Epilepsy, supported by the European Advocates for Epilepsy MEP ad hoc group.



epilepsy.org



#epilepsyday SELFIE ALBUM 2015

Hundreds of people took 'Selfies' photos to celebrate the day. Here is a small sample of great personal images from all corners of the world.



Canada



Philippines



UK



European Parliament



USA Ireland



Australia



Malaysia



Ireland



Bringing International Epilepsy Day 2015 to the European Parliament

Carlos Moedas, EU Commissioner for Research, launches a week-long exhibition in the Parliament

In the developed world our societies must be exemplary in removing obstacles rather than perpetuating them and in developing countries the fear, prejudice and suspicion surrounding conditions like epilepsy must be countered with education. Throughout the world, people have the right to discrete, effective and affordable treatment.

Above all, it's important to demystify epilepsy. There are many great role models and inspiring civil society organisations taking part in world #EpilepsyDay, 9 February 2015. People who don't let epilepsy hold them back from life. But we as governments and public institutions shouldn't allow them to be held back either.

Our efforts should enable every citizen equal opportunity to participate in society and experience life to the fullest.



Media Statistics 2015

22,119,926

The number of Twitter accounts the hashtag reached.
Which means that over

22 million people

have seen some mention of
#epilepsyday!

Facebook and Twitter

- #epilepsyday hashtag was used **6,529** times with nearly **4,700** of those on 9th February
- There were a further **4,500** tweets interacting with tweets mentioning #epilepsyday.
- We had **654** Following our Twitter account and **346** Followers
- We had **4,964** Facebook likes

Website Stats

Visits

The website has been visited by **6,350** people in the week around the day with **22,130** page views!

Backlinks

412 websites linked directly to epilepsy.org

Other Media Exposure

- Around the world national radio, TV, online and printed newspapers carried stories and reports about epilepsy, with an emphasis of the personal stories of those living with the disease.
- The British Medical Journal (BMJ) carried a special report on International Epilepsy Day to mark the event



International Epilepsy Day

Getting ready for 2016!

Some of our Plans!

- In 2016 we are planning to build on the tremendous success of the first International Epilepsy Day, which was made possible due to the involvement of so many chapters around the world, and to make the activities already in place even bigger and better.
- We are further developing many of the initiatives that proved popular and will provide chapters with an even wider range of materials for adoption and adaptation to suit local situations
- Our theme - **Epilepsy is more than Seizures** - which featured on the International Epilepsy Day poster for 2015 and which was translated into almost 30 different languages - will continue to be used.
- **#epilepsyday** will be used again on Social Media.
- The International Epilepsy Day **logo** is available for use by chapters in their activities to celebrate the day. We have changed the colouring on the logo text and this will also be reflected on the International Epilepsy Day website.
- But we are also working on new activities:
 - We are introducing a new sub-theme - **Yes, I can!** - which was launched in Istanbul at the International Epilepsy Congress in early September 2015. This will allow us to highlight how people with epilepsy have achieved great things despite a diagnosis of epilepsy.
 - A new and exciting **International Epilepsy Day mascot** is being created. Campi the seahorse (hippocampus) will pop up all over the place next February. You can find out more about Campi on page 9.
 - A **photography competition** has already been launched, with a prize fund of US\$2,000. The competition echos the sub-theme **Yes, I can!** You will have received information about the q competition and we hope you will be able to promote it through your association's website and social media platforms. Find out more on page 11.
 - The **epilepsy.org** site is being redesigned. New features will include a photo gallery and you might find Campi appearing there as well!
 - A new exhibition will be mounted in the **European Parliament**, using photographs from the **Yes, I can!** photography competition. The exhibition will run during the first week in February and we are busy making plans for this event.
 - **New posters are** being created and these will be available to use and adaptation at local level. Like 2015, we will be happy to provide translations of posters, ready for use by your association.
 - In 2015, we told the **moving stories** of 10 people living with epilepsy. We will expand these stories and also look for new personal testimonies. And we will be looking for your help on this!



INTERNATIONAL EPILEPSY DAY

Monday 8 February 2016

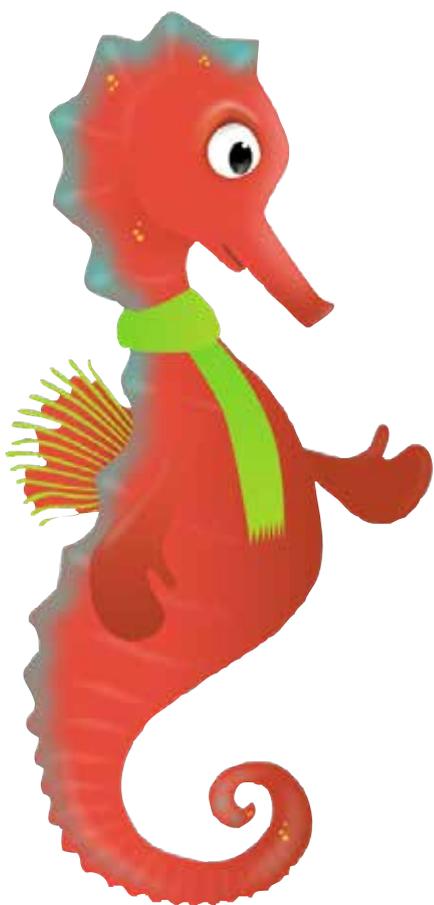


YES, I can!

Overcome stigma and discrimination

@IntEpilepsyDay #epilepsyday

One of our new posters. This poster is being provided to all chapters. Would you like us to help with a translation to your language? Would you like to have a translation of 'Yes, I can' added to one of the hands in your language, if it is not already included? Just ask and we are happy to help!



Creating CAMPI

A Mascot for International Epilepsy Day

Why a Mascot?

An attractive mascot will generate interest and publicity and help to further promote the day. It can be used as the basis of an educational tool to narrate stories about epilepsy that could be used by IBE chapters, such as in school programmes.

Why the Seahorse

The Seahorse is genus Hippocampus and its shape resembles a part of the brain which has the same name and is important in producing seizures and epilepsy.

It's an animal that people find fascinating, graceful and beautiful. It appears in ancient mythology and sculpture as well as in modern children's story-books.

Roll Out

The International Epilepsy Day Mascot would have a gradual roll out over the next few years, with a first appearance in 2016.

Year One

- Work on creating an animated version of Campi is already well advanced. The little creature, and some of his friends, will appear on the epilepsy.org website when the redesign is complete!
- It will also be used on other materials connected to the day.

Following years

After the launch of Campi next year, we will continue to develop ideas and plans for Campi so that it becomes the recognisable mascot of International Epilepsy Day.