### International Epilepsy Day

#### February 10, 2025

International Epilepsy Day helps raise awareness of epilepsy around the world. On International Epilepsy Day the International League Against Epilepsy and the International Bureau for Epilepsy united to call for an accelerated implementation on the World Health Organization's Intersectoral Global Action Plan on Epilepsy and other Neurological Disorders (IGAP).

One of the major global targets of IGAP states that, by 2031, countries will have increased service coverage for epilepsy by 50%.

The second epilepsy specific goal of IGAP states that, by 2031, 80% of countries will have developed or updated their legislation with a view of promoting and protecting the human rights of people with epilepsy.

Read more at <u>https://www.ilae.org/news-and-media/news-about-ilae/ilae-ibe-joint-statement-on-international-epilepsy-day-2025</u>

# National Plan for Epilepsy Act

This act was introduced in congress in February 2025. Over 120 epilepsy organizations applauded its introduction. The National Plan aims to support the 3.4 million people living with epilepsy in the U.S. through a unified approach. The act supports the development of a comprehensive strategy to prevent, diagnose, treat, and cure epilepsy and improve the well-being of people with epilepsy and their families.

If passed by congress and signed into law by the President, this bill will direct the federal government to develop a National Plan for Epilepsy. This plan will enable the federal coordination necessary to ensure better outcomes for people with epilepsy and prioritize the development of more effective epilepsy treatments.

Read more at <u>https://www.epilepsy.com/stories/over-120-epilepsy-organizations-applaud-introduction-national-plan-epilepsy-act-congress</u>

## Cell and Gene Therapy

An important area of interest for new therapeutic development in epilepsy is cell therapy, gene therapy, and other advanced modalities such as RNA therapy. A number of companies and academic institutions are now pursuing the development of such advanced treatments, with several clinical trials currently active.

Read more at <u>https://www.cgtlive.com/view/international-epilepsy-day-2025-looking-back-progress-cell-gene-therapy</u>

#### **Optogenetics**

Researchers at UCSF, UCSC, and UC Berkeley use pulses of light to switch neurons off and curb abnormal neural activity. Eventually, they hope the technique will replace surgery providing a less invasive option for patients whose symptoms cannot be controlled with medication.

Read more at <u>https://www.ucsf.edu/news/2024/11/428896/how-optogenetics-can-put-brakes-epilepsy-seizures</u>

#### Ketamine Trial

Scientists have received the initial funding for a trial to start this summer and will last 4.5 years. The trial will investigate the use of ketamine for status epilepticus in both adults and children.

Read more at <u>https://www.epilepsy.org.uk/news/ketamine-to-be-trialled-for-status-epilepticus-in-adults-and-children-us</u>

## Post-Traumatic Epilepsy

A new international study has unveiled critical insights in understanding Post-Traumatic Epilepsy, a condition that can develop after a traumatic brain injury. The study highlights the important role played by a receptor in the brain. It suggests how we could both reduce epilepsy risk and predict which patients are most at risk of developing PTE.

Read more at <u>https://www.rcsi.com/dublin/news-and-events/news/news-</u> article/2025/01/research-offers-hope-for-preventing-epilepsy-after-brain-injury

#### Personalized Epilepsy Treatments

Research led by UTHealth Houston scientists has uncovered two genes associated with variants linked to epilepsy, which showed specific traits that make them promising diagnostic biomarkers. By linking epilepsy to specific genetic mutations, the research offers a new framework for understanding the disorder and developing therapies that address its root causes.

Read more at <u>https://medicalxpress.com/news/2025-01-genetic-discovery-personalized-epilepsy-treatments.html#google\_vignette</u>

# Fenfluramine for LGS

Epilepsy medication fenfluramine available for patients with Lennox-Gastaut syndrome in England. The National Institute for Care and Excellence has recommended it as a treatment for seizures in LGS for people aged two years and over.

Read more at <u>https://www.epilepsy.org.uk/news/fenfluramine-available-on-nhs-for-rare-form-of-epilepsy-lgs</u>

All websites accessed on February 21, 2025.

# Local Epilepsy Families Upcoming Events

- Brainstorm walk/run held annually the last Sunday in June
- Art therapy held every other Saturday, next session Saturday, February 22
- Purple Picnic- held annually in August

Any other suggestions or activities we could offer would be appreciated.