



EpiCARE

The European Reference Network for
Rare and Complex Epilepsies

Newsletter

May 2026

Stay up to date on our upcoming events, educational and research activities, calls, and news from the coordination team, clinicians, researchers, nurses and Patient Advocate community. Feel free to **forward** this newsletter, and sign up [here](#) to receive it regularly!

Next interactive webinar

What is a Disease Modifier? Pills from real-world treatment of DEEs

Date: **25 June 2026** / 17pm - 18:30pm

Speakers: Matthew Walker (University College London, UK), Pasquale Striano (Istituto Giannina Gaslini, Italy), Katarzyna Kotulska (The Children's Memorial Health Institute, Poland), Valentina De Giorgis (Fondazione Istituto Neurologico Nazionale Casimiro Mondino, Italy), Antonella Riva and Ganna Balagura (Istituto Giannina Gaslini, Italy), and Gaetan Lesca (Hospices Civils de Lyon, France).

[Register here](#)



Latest news

The International Conference on Tuberous Sclerosis Complex and other Neurocutaneous Conditions

Last week (21-23 May, 2026) took place in Warsaw The International Conference on Tuberous Sclerosis Complex and other Neurocutaneous Conditions. The conference was under the patronage of EpiCARE.

About **200 participants** from **Europe, USA and Asia** attended the Conference. Among them, members of EpiCARE, Rima Nabbout, Lieven Lagae, Katarzyna Kotulska, Sergiusz Jozwiak, and 8 recipients of the Manuel Gomez Award of Tuberous Sclerosis Alliance.



Do not hesitate to share the below survey done by E+A to your patients

The E+A SURVEY:
IDENTIFYING THE TRUE BURDEN

The survey is designed to collect robust data to move beyond seizures and understand the global impact of complex and rare epilepsies.

FOUR CRITICAL DOMAINS

DAILY CHALLENGES CAREGIVER NEEDS QUALITY OF LIFE ACCESS TO CARE

DRIVING POLICY CHANGE:
Survey findings will be launched at the 16th European Epilepsy Congress in Athens, on September 2026.

AVAILABLE IN 15 LANGUAGES!

TAKE THE E+ SURVEY NOW
and make your story visible.

PART 1 PART 2

YOUR VOICE IS IMPORTANT!

www.epilepsyplus.org @epilepsyplus Epilepsy Plus - E+ Epilepsy Plus - E+

Upcoming events 2026 endorsed by ERN EpiCARE

12th Congress of the European Academy of Neurology June 27 - 30, 2026 / Geneva (Switzerland)

The European Academy of Neurology (EAN) Congress is one of the world's leading events in neurology. This annual hybrid meeting brings together clinicians, researchers, educators, industry partners, residents, students, and patient representatives for four days of cutting-edge science and professional development. [Register now!](#)



EPNS Research Meeting 2026 June 16 - 17, 2026 / Thessaloniki (Greece)

Join us in Thessaloniki for the unique [European Paediatric Neurology Society \(EPNS\) Research Meeting 2026](#), featuring plenary lectures from leading experts and interactive sessions, including two break-out sessions with five parallel working groups covering Autoimmune & Infectious Diseases, Developmental Neurology & Neurogenetics, **Epilepsy**, Fetal & Neonatal Neurology, Leukodystrophies, Movement Disorders, Neurometabolic, and Neuromuscular disorders. **Registration is now Open** on a 1st come/1st served basis to paediatric neurology clinicians and researchers at all career stages—from trainees and PhD students to senior experts—this meeting offers an excellent opportunity for knowledge sharing and discussion, with the potential to develop and strengthen future collaborative research projects.

Know EpiCARE Working groups!

Working Group 5: Neuropsychology

Epilepsy is more than having seizures. Behavioral and cognitive comorbidities are very common and sometimes affect everyday life and functioning more than seizures.

WG 5 webpage



ERN EpiCARE Supporting Next Generation Epilepsy Experts

An important mission of EpiCARE is to **support the education and training of early-career experts** in the field of rare and complex epilepsies. One concrete action toward this aim is to support EpiCARE members in [presenting their work](#) at major scientific congresses in Europe:

- [16th European Epilepsy Congress](#)
 - [In Search of Lost Time Workshop 7](#)
- Deadline: September 13th

International Epilepsy Congress, Lisbon (Portugal) - August 30 - September 3 (2025)

Lisa Brijunić (University of Zagreb, Croatia) presented her research on the topic of 'Epilepsy and Mental Health' at the International Epilepsy Congress in Lisbon, Portugal. She was able to present her work and meet other experts in the field. She also attended the 'In Search of Lost Time' workshop, which was a great opportunity to learn from other experts and to share her own experiences. She was very happy to participate in the congress and to meet other experts in the field.

Watch videos of our testimonials!

EpiCARE Scientific Publications

[Developmental and/or epileptic encephalopathy with spike-and-wave activation in sleep: Pathophysiological insights and treatment options](#)

Specchio N, Auvin S, Brunklaus A, De Giorgis V, Di Micco V, Gardella E, Jansen FE, Nabbout R, Pepi C, Rubboli G, Trivisano M, Curatolo P. April 2026.

[Current management of low-grade, epilepsy-associated brain tumors in Europe](#)

Arzimanoglou A, Tchaicha S, Trebino Harrington B, Mühlebner A, Najm I, Blümcke I. April 2026.

[Informed acceptance and perceptions of the 2025 ILAE seizure classification following structured teaching](#)

Beniczky S, Malenica M, Lawrence N, San Antonio-Arce V, Norvell J, Cross H, Trinka E. *Epileptic Disorders*

[Risk of neurodevelopmental disorders associated with paternal use of valproate during spermatogenesis: a living meta-analysis—version 1](#)

Christensen J, Trabjerg BB, van Gelder MMHJ, Meng LC, Lai HY, Igland J, Razaz N, Thomson T, Bjørk MH, Hsiao FY, Nordeng HME, Dreier JW.

You can consult recent publications related to the diagnosis and treatment of rare and complex epilepsies on our [scientific publications webpage](#).

ANYTHING TO SHARE?

Any news you would like to share, events planned, publications in the works? Share with us any information you would like us to include in the next newsletter at l.roig@epi-care.eu

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