



EpiCARE

The European Reference Network for
Rare and Complex Epilepsies

Newsletter

November 2025

If you want to be informed about our next events, educational and research activities, calls, but also receive news from the coordination team, our clinicians, researchers, nurses and our Patient Advocate community...don't miss this **Newsletter!**

Feel free to **forward** this newsletter... and here is the [link to sign up](#) and receive it regularly!

Next webinar

"How to Amplify the Voices of Patients and Caregivers in the Rare and Complex Epilepsies Community"

Date: **18 December 2025**

Presented by: Isabella Brambilla, Sandra Silva, Małgorzata Kosła, Carol Anne Partridge (EpiCARE Patients Advocacy Group)



Patient Journeys
and Leaflets

[Register here](#)

 You can now request a **certificate of attendance** after registering for and attending the webinars! Please email the [EpiCARE Helpdesk](#) afterward, and we'll send it to you.

Latest news

In Search of Lost Time 6 - Rome, 11 - 13th 2025

From 11th to 13th November, the "In Search of Lost Time 6" workshop was held at the Istituto Patristico Augustinianum in Rome, organized by Italian epilepsy centres and endorsed by the International League Against Epilepsy and ERN EpiCARE. This year's edition covered the topics of **fever-induced epilepsies**, **gene therapies in DEEs**, and **artificial intelligence in epilepsy care**. For the first time, **patient representatives** rather than having a separate session were invited to share their views on the 3 topics and were actively involved in every session. The event concluded with presentations from early-career researchers, two of whom were **supported by EpiCARE**.

 **Save the dates of the 7th edition: November 11th - 13th 2026**



Taking advantage of being in Rome, some EpiCARE working groups held important meetings...

WG15 Research meeting

29 participants from different EpiCARE centres were supported to attend the **Research Think Tank meeting**, marking the first step toward a new collaborative group of early- and mid-career clinicians and researchers. The objective was to encourage open and creative brainstorming on future collaborative research projects and grant opportunities, generating innovative ideas that align their translational interests and expertise with EpiCARE's research priorities.



WG13 Guidelines meeting

The EpiCARE Guidelines training workshop, ***From Data Extraction and Quality Assessment to Drafting Evidence-Based Recommendations***, took place on Friday and Saturday at the Starhotel Michelangelo. Following the GRADE methodology, the workshop was a great success for transversal guideline production, strengthening the overall guideline development process.



High-Level Meeting on Rare Diseases 2025, EU Parliament Brussels December 9th-11th, 2025

Do not miss to promote and follow the upcoming High Level Meeting on Rare Diseases, of which ERN EpiCARE is a partner.

Convened by MEP Vytenis Andriukaitis, ERN Coordinators and the Brains for Brain Foundation and supported by active stakeholders in the rare disease ecosystem, this action aims to:

- Strengthen the ERN ecosystem while driving innovation, accelerating care, research, and collection of scientific and clinical data.
- Ensure equity across Member States regardless of their resources, data infrastructure, or scientific and financial capacities.
- Improve the chances for every patient with a rare, low-prevalence, or complex disease to access timely to diagnosis and targeted advanced treatments.

An EU Declaration will be adopted on the European Research and Innovation Ecosystem for Rare and Complex Diseases.
Register now ([in-person or online attendance](#))



Last call! 🌟 Submit your proposals for the EEC 2026 Athens Deadline: 8/12/2025

The Scientific and Organising Committee (SOC) is pleased to announce the **call for proposals** for **EEC Fora** as part of the [European Epilepsy Congress 2026 \(Athens, Greece, 5-9 September 2026\)](#) programme. EEC Fora will offer a unique opportunity to explore **specialised topics** in a highly interactive and informal setting, including workshops, debates, lightning sessions, or campfire-style discussions. [Submit your proposal!](#)

Upcoming events 2025

AES Annual Meeting

 **December 5 - 9th** 📍 **Atlanta (USA)**

The [AES \(American Epilepsy Society\) Annual Meeting](#) brings together healthcare providers, scientists, advocates, industry professionals, and others dedicated to improving outcomes for people with epilepsy. It is the largest epilepsy-focused event in the United States!

Advanced Imaging in Epilepsy course (LICE)

December 12 - 14th 📍 **Rome (Italy)**

The [4th Advanced Imaging in Epilepsy Course](#) focuses on the use of SWANe - Standardized Workflow for Advanced NeuroImaging in Epilepsy - a software tool developed to support the identification and analysis of the epileptogenic zone and network in patients with focal epilepsy, including rare and complex forms.

EpiCARE Scientific Publications

Clobazam versus corticosteroid for developmental and epileptic encephalopathy with spike-wave activation in sleep ((D)EE-SWAS): Results of a multicenter observational study

Epilepsia

Research Article

Clozhazam versus corticosteroid for developmental and epileptic encephalopathy with spike-wave activation in sleep ((D)EE-SWAS): Results of a multicenter observational study

Mateen M. L. van Arnhem¹ | Lijde J. Vijn² | Guido Rubboli² | Martina Søndergaard M. Khinchi³ | Pavia Dimova⁴ | Emilio Perucca⁵ | Valentina De Giorgis⁶ | Lina Metsähonkala⁷ | Georgia Karamantani⁸ | Anna Sanaa⁹ | Richard Chiu¹⁰ | Lieven Lazez¹¹ | Aleksis Azilmanoglou¹² | Wim M. Otte¹³ | Frans S. Leffers¹⁴ | Heloén C. van Teseeling¹⁵ | Kees P. J. Braun¹⁶ | Floris E. Jansen¹⁷ | Bert van den Munckhof¹⁸

Abstract
Objective: Developmental and epileptic encephalopathy with spike-wave activation in sleep ((D)EE-SWAS) is a rare disorder with unclear aetiology and treatment. The International League Against Epilepsy (ILAE) defines (D)EE-SWAS as a form of developmental and epileptic encephalopathy with spike-wave activation in sleep. This study aims to evaluate the efficacy of clozapine versus corticosteroids in the treatment of (D)EE-SWAS. Methods: This multicenter observational study included 20 patients with (D)EE-SWAS who were treated with either clozapine or corticosteroids. Results: The study included 20 patients with (D)EE-SWAS. The majority of patients were treated with clozapine. The efficacy of clozapine was compared to that of corticosteroids. Conclusions: The study found that clozapine was more effective than corticosteroids in the treatment of (D)EE-SWAS.

Authors: L. van Arnhem M, Vijn L, Rubboli G, Søndergaard M, Khinchi M, Dimova P, Perucca E, De Giorgis V, Metsähonkala L, Karamantani G, Jansen A, Chin R, Lagae L, Arzimanoglou A, Otte W, Leijten F, C. van Teseeling H, Braun K, Jansen F, van den Munckhof B.

[Read it now!](#)

Lennox–Gastaut syndrome unveiled: Advancing diagnosis, therapies, and advocacy-insights from the Genoa International Workshop

Epilepsia

Critical Review

Lennox–Gastaut syndrome unveiled: Advancing diagnosis, therapies, and advocacy-insights from the Genoa International Workshop

Antonella Riva^{1,2} | Gianluca D’Onofrio³ | Elisabetta Amadori^{1,2} | Alexis Arzimanoglou⁴ | Stéphanie Auvry^{5,6,7} | Irene Riguzzi⁸ | Paola Barbin⁹ | Valentina Biagioli¹⁰ | Isabella Brambilla^{11,12} | Giuliana Cangemi¹³ | Antonietta Coppola¹⁴ | Antonella De Lillo¹⁵ | Carlo Di Bonaventura¹⁶ | Giancarlo Di Genaro¹⁷ | Edoardo Ferlazzo^{18,19} | Antonio Gil-Nagel^{20,21} | Giuseppe Gobbi^{22,23} | Simona Lattanzi²⁴ | Gerhard Kluger^{25,26} | Günter Kramer²⁷ | Maria Margherita Mancardi²⁸ | Carlo Minetti¹ | Lino Nobili²⁹ | Elisa Paravati³⁰ | Milka Pringsheim^{31,32} | Erika Rebeschke³³ | Antonino Romeo^{34,35} | Angelo Russo³⁶ | Emilio Russo³⁷ | Katia Santoro³⁸ | Susanne Schubert-Bast^{39,40} | Laura Siri⁴¹ | Jo Sourbron^{42,43} | Maria Stella Vari⁴⁴ | Alberto Verrotti⁴⁵ | Flavio Villani⁴⁶ | Maurizio Viri⁴⁷ | Celina von Stülpnagel⁴⁸ | Nella Zamponi⁴⁹ | Federico Zara⁵⁰ | Pasquale Striano^{51,52}

Abstract
Lennox–Gastaut syndrome (LGS) is one of the most severe, yet one of the most discussed, childhood-onset developmental and epileptic encephalopathies (DEEs). Disease among epileptologists on the definition and etiopathology of LGS is heterogeneous, which could make its recognition inconsistent. However, in recent years, new diagnostic strategies, including both high-resolution magnetic resonance imaging and next-generation sequencing techniques, have enabled

Authors: Riva A, D’Onofrio G, Amadori E, Arzimanoglou A, Auvin S, Bagnasco I, Barabino P, Biagioli V, Brambilla I, Cangemi G, Coppola A, De lillo A, Di Bonaventura C, Di Gennaro G, Ferlazzo E, Gil-Nagel A, Gobbi G, Lattanzi S, Kluger G, Krämer G, Margherita M, Minetti C, Nobili L, Paravati E, Pringsheim M, Rebessi E, Romeo A, Russo A, Russo E, Santoro K, Schubert-Bast S, Siri L, Sourbron J, Stella M, Verotti A, Villani F, Viri M, Stülpnagel C, Zamponi N, Zara F, Striano P.

[Read it now!](#)

Natural History of Alternating Hemiplegia of Childhood: Vulnerabilities in Early Childhood and Predictive Factors for Long-Term Outcomes

Annals of the Child Neurology Society

Research Article

Natural History of Alternating Hemiplegia of Childhood: Vulnerabilities in Early Childhood and Predictive Factors for Long-Term Outcomes

Shih H. Tsai¹ | Hsiang-Feng Tsai² | Szu-Yi Lin³ | Chuan-Tsun Tsai⁴ | Tzong-Hong Jou⁵ | Hsiang-Feng Tsai⁶ | Anshu Bhatia⁷ | Hsiang-Feng Tsai⁸ | Anshu Bhatia⁹ | Hsiang-Feng Tsai¹⁰ | Hsiang-Feng Tsai¹¹ | Hsiang-Feng Tsai¹² | Hsiang-Feng Tsai¹³ | Hsiang-Feng Tsai¹⁴ | Hsiang-Feng Tsai¹⁵ | Hsiang-Feng Tsai¹⁶ | Hsiang-Feng Tsai¹⁷ | Hsiang-Feng Tsai¹⁸ | Hsiang-Feng Tsai¹⁹ | Hsiang-Feng Tsai²⁰ | Hsiang-Feng Tsai²¹ | Hsiang-Feng Tsai²² | Hsiang-Feng Tsai²³ | Hsiang-Feng Tsai²⁴ | Hsiang-Feng Tsai²⁵ | Hsiang-Feng Tsai²⁶ | Hsiang-Feng Tsai²⁷ | Hsiang-Feng Tsai²⁸ | Hsiang-Feng Tsai²⁹ | Hsiang-Feng Tsai³⁰ | Hsiang-Feng Tsai³¹ | Hsiang-Feng Tsai³² | Hsiang-Feng Tsai³³ | Hsiang-Feng Tsai³⁴ | Hsiang-Feng Tsai³⁵ | Hsiang-Feng Tsai³⁶ | Hsiang-Feng Tsai³⁷ | Hsiang-Feng Tsai³⁸ | Hsiang-Feng Tsai³⁹ | Hsiang-Feng Tsai⁴⁰ | Hsiang-Feng Tsai⁴¹ | Hsiang-Feng Tsai⁴² | Hsiang-Feng Tsai⁴³ | Hsiang-Feng Tsai⁴⁴ | Hsiang-Feng Tsai⁴⁵ | Hsiang-Feng Tsai⁴⁶ | Hsiang-Feng Tsai⁴⁷ | Hsiang-Feng Tsai⁴⁸ | Hsiang-Feng Tsai⁴⁹ | Hsiang-Feng Tsai⁵⁰ | Hsiang-Feng Tsai⁵¹ | Hsiang-Feng Tsai⁵² | Hsiang-Feng Tsai⁵³ | Hsiang-Feng Tsai⁵⁴ | Hsiang-Feng Tsai⁵⁵ | Hsiang-Feng Tsai⁵⁶ | Hsiang-Feng Tsai⁵⁷ | Hsiang-Feng Tsai⁵⁸ | Hsiang-Feng Tsai⁵⁹ | Hsiang-Feng Tsai⁶⁰ | Hsiang-Feng Tsai⁶¹ | Hsiang-Feng Tsai⁶² | Hsiang-Feng Tsai⁶³ | Hsiang-Feng Tsai⁶⁴ | Hsiang-Feng Tsai⁶⁵ | Hsiang-Feng Tsai⁶⁶ | Hsiang-Feng Tsai⁶⁷ | Hsiang-Feng Tsai⁶⁸ | Hsiang-Feng Tsai⁶⁹ | Hsiang-Feng Tsai⁷⁰ | Hsiang-Feng Tsai⁷¹ | Hsiang-Feng Tsai⁷² | Hsiang-Feng Tsai⁷³ | Hsiang-Feng Tsai⁷⁴ | Hsiang-Feng Tsai⁷⁵ | Hsiang-Feng Tsai⁷⁶ | Hsiang-Feng Tsai⁷⁷ | Hsiang-Feng Tsai⁷⁸ | Hsiang-Feng Tsai⁷⁹ | Hsiang-Feng Tsai⁸⁰ | Hsiang-Feng Tsai⁸¹ | Hsiang-Feng Tsai⁸² | Hsiang-Feng Tsai⁸³ | Hsiang-Feng Tsai⁸⁴ | Hsiang-Feng Tsai⁸⁵ | Hsiang-Feng Tsai⁸⁶ | Hsiang-Feng Tsai⁸⁷ | Hsiang-Feng Tsai⁸⁸ | Hsiang-Feng Tsai⁸⁹ | Hsiang-Feng Tsai⁹⁰ | Hsiang-Feng Tsai⁹¹ | Hsiang-Feng Tsai⁹² | Hsiang-Feng Tsai⁹³ | Hsiang-Feng Tsai⁹⁴ | Hsiang-Feng Tsai⁹⁵ | Hsiang-Feng Tsai⁹⁶ | Hsiang-Feng Tsai⁹⁷ | Hsiang-Feng Tsai⁹⁸ | Hsiang-Feng Tsai⁹⁹ | Hsiang-Feng Tsai¹⁰⁰

Authors: Patel S, Panagiotakaki E, Liu B, Fons C, Prange L, Papadopoulou M, Boggs A, De Grandis E, Vezyroglou A, Fortunato F, Balestrini S, Ragona F, Julia E, Zucca C, Garone G, Megvinov A, Lo Bosco G, Stagnaro M, Uchitel J, Comajuan M, Athina M, Anticono J, Jasien J, Wuchich J, Johannesson S, Narayan J, Cross H, Sisodiya S, Hong H, Arzimanoglou A, Vavassori R, Mikati M.

[Read it now!](#)

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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