



Newsletter EpiCARE

January 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 - 13th February

'The Ukraine Experience'

 **DATE**
13th February 2025

 **TIME**
17 - 18:30PM

 **MODALITY**
Online

 **PRESENTED BY**
Andriy Dubenko
and Volodymyr Kharytonov



[Register here](#)

We are honoured to host again, [one year later](#), two esteemed colleagues, Professors **Andriy Dubenko** and **Volodymyr Kharytonov**, who are also members of the Ukrainian chapter of the International League Against Epilepsy, to share their experiences during these challenging years of war. We deeply admire their unwavering dedication to epilepsy care and their efforts to maintain access to treatment despite the ongoing difficulties.

Our webinars take place **once a month**, and [the recordings are always available on our website](#). You can check the program of the upcoming webinars and register to the mailing on the webpage.

Latest news

International Epilepsy Day - February 10th 2025

International Epilepsy Day, organized annually by the **International Bureau for Epilepsy (IBE)** and the **ILAE**, will take place on **February 10**. If you're planning an event, **promote it** with the International Epilepsy Day **logo** and raise awareness by posting on social media with the hashtag **#EpilepsyDay**, tagging IBE, ILAE and EpiCARE for wider visibility and support.



International
Epilepsy Day

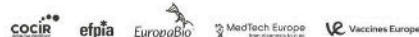
Official Launch of the Realised Project

On January 9-10, 2025, the launch of the [Realised IHI Project](#) marked a significant milestone for clinical trials in rare and ultra-rare diseases. EpiCARE, involved in key areas of the project (WP2, WP3 and WP11), traveled to **Vienna** (Austria) to attend the **Realised kick-off meeting** at Sigmund Freud University. Over 300 million people worldwide, including 30 million in Europe, live with a rare disease. Most of these are ultra-rare and have no treatment options. The Realised IHI project is here to change that. This European public-private partnership formed by nearly 40 partners, is on a mission **to optimise and accelerate the development of treatments for rare and ultra-rare conditions**.

Transforming Clinical Trials in Ultra-Rare Diseases



Realise D



The project is funded by the European Union's Horizon Europe research and innovation programme under the Marie Skłodowska Curie grant agreement No 101019719. The activities are supported by the European Union's Horizon Europe research and innovation programme under the Marie Skłodowska Curie grant agreement No 101019719. The project is also supported by the European Union's Horizon Europe research and innovation programme under the Marie Skłodowska Curie grant agreement No 101019719. The project is also supported by the European Union's Horizon Europe research and innovation programme under the Marie Skłodowska Curie grant agreement No 101019719.



“Beyond Seizures: Advancing Holistic Care for Rare and Complex Epilepsies” Workshop (26-27th May 2025 – Alesund, Norway)

This workshop focuses on the **challenges beyond seizure control**, including neurodevelopmental, cognitive, mental health, and quality-of-life impacts. Organized by the “Beyond Seizures” EpiCARE Working Group, it promotes an interdisciplinary approach to understanding and addressing these complex issues in patients with Developmental and Epileptic Encephalopathies (DEEs) and Drug-Resistant Epilepsies (DRE), highlighting the profound effects on patients, families, and caregivers. The [session schedule](#) is now available for consultation. You can [register through this link!](#)

WORKSHOP «BEYOND SEIZURE»

26 - 27th May in Aalesund, Norway 2025

The workshop is open to healthcare workers with special interest in «Beyond seizures» issues in complex and rare epilepsies.

- There is no congress fee, but travelling and accomodation must be covered at your own expense.
- There are limited vacancies at this conference hotel, so please make your reservation in time. The conference however, can hold up to 200 participants.
- If our conferece hotel is fully booked, other hotels are close by, but you have to book it yourself.



SCIENTIFIC COMMITTEE:



MORTEN I. LOSSIUS



CHRISTOPH HELMSTAEDTER



SVERRE MYREN



SERGIUSZ JOZWIAK



Endorsed by the European Reference Network for rare and complex epilepsies



Calls for collaborative Genetic Research

New Calls for collaborative genetic research on rare and complex epilepsies are available on the [EpiCARE website](#). Visit it for more information on each one:

Alexandru-Ştefan Niculae, Diana Gabriela Bărcă, Professor Dana Craiu

- **Genotype - phenotype correlation and phenotypic characterization of patients with *KCNQ1* variants**

Allan Bayat - Danish Epilepsy Centre, Filadelfia

- Understanding KCNH1 - related disorders: translating genetic diagnostics into personalized treatment
- Understanding PIG´opathies, GPI-anchoring disorders of glycosylation
- GRIA Genes

Robert Lauerer-Braun, Holger Lerche, Elena Kuster - University Hospital Tübingen, Germany

- **DECADE - Deciphering the CACNA1E developmental and epilepticencephalopathy**

Reza Maroofian, Amy McTague, Henry Houlden - Department of Neuromuscular Diseases UCL Queen Square Institute of Neurology and UCL GOS Institute of Child Health

- **Characterization of the Clinical and Natural History of UFSP2-Related Developmental and Epileptic-Dyskinetic Encephalopathy**

Upcoming events

February 2025

* Neurodevelopmental Syndromes and Movement Disorders

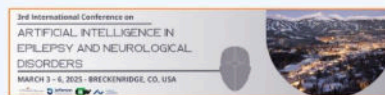
 *Barcelona (Spain)*
 *6 - 7 February*



March 2025

* 3rd Conference on Artificial Intelligence in Epilepsy and Neurological Disorders

 *Breckenridge (Colorado)*
 *3 - 6 March*



The international Symposium on Neurodevelopmental Syndromes and Movement Disorders, endorsed by the ERN EpiCARE and the ERN-RND

*"Join us in **Barcelona**, or **remotely**, for the [International Symposium on Neurodevelopmental Syndromes and Movement Disorders](#) from **February 6-7, 2025**, Explore the latest insights into neurodevelopmental and movement disorders, including their neurobiological basis, behavioural impacts, and comorbidities across the lifespan. This event brings together leading experts to foster collaboration and advancements in the field! Tempted by our program? Hurry up! Join us and register [here](#)".*

Save the date: 16th European Epilepsy Congress, Athens (Greece)

The 16th European Epilepsy Congress will take place in Athens, Greece from September **5th - 9th 2026**. Call for [session proposals submissions](#) are open by **7 February 7th 2025!**

Education and Training

April 23-26: Save the date and join the EPIPED Course in Girona

Treatment Strategies in Pediatric Epilepsies (cycle 2024-2026). A unique, international training course designed to bridge geographical and knowledge gaps in epilepsy care. It aims to regularly update **neurologists** and **child neurologists** on the best practices when treating children and adolescents with epilepsy.

Discover [the full program](#) of this 3-year cycle and be part of this transformative learning experience. [Register here!](#)

EPIPED COURSE TREATMENT STRATEGIES IN PAEDIATRIC EPILEPSIES

April 23-26
2025
Girona
Spain

a 3 year-cycle international interactive training course

Organised by the Paediatric Epilepsy Departments of the Hospital San Juan de Dios, Barcelona, Spain and the Sestre milosrdnice UHC, Zagreb, Croatia.



3rd cycle EPIPED Course - 2nd year

ERN EpiCARE Supporting Next Generation Epilepsy Experts

An important mission of EpiCARE is to **support the education and training of young doctors and researchers** already working in the **field of rare and complex epilepsies**. One concrete actions toward this aim is to support participants in presenting their work at major **scientific congresses in Europe**.

Next congresses available 2025

*Congress of the
European Academy
of Neurology

Helsinki, Finland
21 - 24 June



*European
Paediatric
Neurology Society

Munich, Germany
8 - 12 July



*International
Epilepsy
Congress

Lisbon, Portugal
30 - 3 September



*In Search of
Lost Time 6
Workshop

Rome, Italy
12 - 14 November



For more information about the **requirements**, [please visit our website](#)

EpiCARE Scientific Publications

We encourage all EpiCARE members to **carefully read** the publication of **Piero Perrucca et al on Epilepsy-Pregnancy Registries**. Experts in epilepsy care need to be regularly updated, referring to scientifically meaningful publications, based on evidence. Particularly on an essential topic such as pregnancy and anti-seizure medications, about which a lot of unfounded information circulates, that can put in danger patients with epilepsy.

Epilepsy-pregnancy registries: An Update

Perucca P, Battino D, Bromley R, Chen L, Craig J, Hernandez S, Holmes L, Koshiy K, Meador K, Menon R, O'Brien T, Pennell P, Zhou D, Tomson T



Basic and preclinical epilepsy research Scientists' perception of clinical epileptology

De Curtis M, Asukile M, Battaglia G, Sellin A, Cavalheiro E, Galovic M, Gelonas J, Ikeda A, Patel M, Perucca P, Potschka H, Rocha L, Triki C, Wilmschurst J, Gaillard W, Deleo F, Cendes F, Cross H, Galanopoulou A, Research & Innovation Task Force of the ILAE.



Epilepsy and employment: A qualitative interview study with heads of human resources and occupational physicians in Austria

Leitinger M, Klampfer C, Obermeyr L, Orav K, Tabaei P, Alexa M, Thomschewski A, Höfler J, Rossini F, Kuchukhidze G, Kalss G, Mauritz M, Poppert K, Toma A, Crespo-Pimentel B, Bosque P, Kobulashvili T, Schwimbeck F, Trinka E.



Transition from pediatric to adult care system in patients with complex epilepsies: Necker model for transition evaluated on 70 consecutive patients

Nabbout R, Molimard A, Scorrano G, Aubart M, Breuillard D, Delaune M, Barcia G, Chermaly N, Barthez M, Desguerre I.

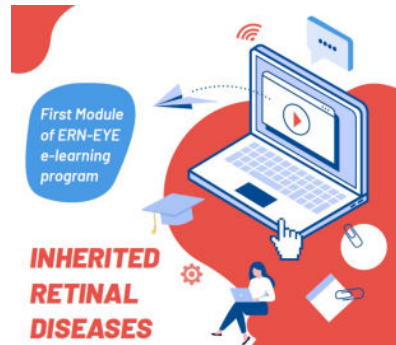


You can consult recent publications on rare and complex epilepsies, epilepsy surgery and other topics on our [scientific publications webpage](#).

News from other ERNs

E-learning course on Inherited Retinal Diseases by European ERN-EYE

The **European ERN-EYE** network is launching its [e-learning course on Inherited Retinal Diseases](#) for the second consecutive year. This year, it is also **open to members of other ERNs!** It is intended for medical staff, especially young doctors and interns. Registration is free and open **until March 14th 2025**. [Here is the registration link](#).



ERN Rare-Liver held its Annual Meeting at Hospital Clínic de Barcelona

On January 23, some EpiCARE members based in Barcelona had the privilege of attending the **ERN Rare-Liver Annual Meeting 2025**, held at **Hospital Clínic de Barcelona, Spain**. We received a warm welcome from the ERN Coordinator, Ansgar W. Lohse, as well as the initial sessions and presentations of the Working Groups. At 5:45 PM, Alexis Arzimanoglou (EpiCARE Coordinator) has been invited to deliver the session titled **"Cross ERN Cooperation"**, emphasizing the importance and benefits of cooperation among the 24 ERNs.



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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