See in browser

Newsletter
EpiCARE
February 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 regulary!

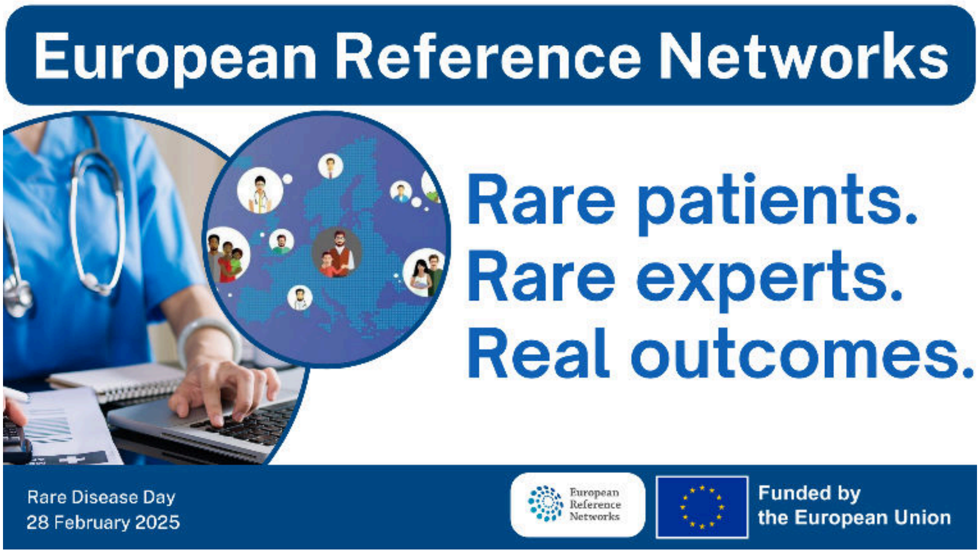
Happy Rare Disease Day! - 28th February 2025

On Rare Disease Day, the **European Commission** released a booklet highlighting the impact of European Reference Networks on patients and families. Two new factsheets on the EU's work and commitments to rare diseases are also available.

- **Factsheet**: *“EU delivering on rare diseases for patients and families”*
- **Factsheet**: *“How the European Commission works on Rare Diseases and the European Reference Networks (ERNs)”.*
- **Booklet**: *“European Reference Networks. A success story for patients living with a rare disease”.*

RARE DISEASE DAY®

European Comission Publications



Next Webinar - 27th March

'How a neuropathologist approaches LEAT'

Webinar

DATE
27th March 2025

TIME
17 - 18:30PM

MODALITY
Online

PRESENTED BY
Angelika Mühlebner

Register here

'How a neuropathologist approaches Low-Grade Epilepsy-Associated Brain Tumors (LEAT), by Angelika Mühlebner at 17pm

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 website.

Latest news

EpiCARE Annual Meeting 2025

It is a pleasure to announce that we already have a date and venue for the ERN EpiCARE Annual Meeting 2025. Our members should save the dates from **June 12th to June 14th**, 2025, because **Salzburg (Austria)** will hold us for the event.
We will give you more details soon!

International Epilepsy Day 2025

On February 10th 2025, we saw members of ERN EpiCARE raising awareness of epilepsy and the challenges faced by those living with or caring for someone with the condition by taking part in numerous activities for International Epilepsy Awareness day.

Want to know more about EpiREG?

The **EpiREG Registry**, developed by the ERN EpiCARE, is a major secured patform for the **collection of anonymized clinical data** from all EpiCARE centers. Under the leadership of the **KUL, Leuven (Belgium)** team, it allows to better understand the epidemiology of rare and complex epilepsies, facilitate natural history studies and treatment-related clinical trials. It can be linked to independent research projects and databases, generating knowledge to improve global epilepsy care.

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:

Sarah Weckhuysen - University Hospital of Antwerp, Antwerp, Belgium

- **Genetic and environmental modifiers associated with KCNQ2-related disorders**
- **Genetic and phenotypic spectrum of FZR1 related disorders**

Benedetta Kassabian, Guido Rubboli, Rikke Steensbjerre Møller,Zeynep Tümer - Danish Epilepsy Centre Filadelfia and Copenhagen University Hospital, Rigshospitalet

- **Genotype-phenotype characterization of DLG4-related synaptopathy**

Fazeli Walid - University Hospital Bonn, Germany

- **Genotype-phenotype characterization of SCN2A associated disorder**

Latest news

Invitation to Join the ERDERA Ethics Advisory Group (EAG)

ERDERA invites their Partners to apply for membership in their **Ethics Advisory Group (EAG)**. The EAG ensures ethical integrity across ERDERA's research activities, providing independent oversight, guidance, and recommendations on ethical, legal, and societal issues. Meetings will be held t**wice a year** (virtual or face-to-face), with additional meetings as needed.

EAG members will: Provide ethical guidance on research design, conduct, and reporting, Advise on patient data protection, consent processes, and emerging technologies, Assess ethical aspects of ERDERA's work packages and provide recommendations…

Eligibility & Commitment: Affiliated with an ERDERA involved organisation, Expertise in bioethics, legal research governance, or patient advocacy, Experience in ethical advisory roles in research or healthcare, Commitment to ethical integrity and inclusive research and Independence of any potential conflicts of interest that may arise for a specific EAG role.

Application form to complete by 07/03/2025

Upcoming events - April 2025

- **Intrace 2025-Charting the Intracranial Connections between Clinics and Neurosciences**
  - Parma (Italy)
  - 1th - 6th
- **STESS 2025**
  - Gothenburg (Sweden)
  - 2th - 4th
- **European Dravet Syndrome Conference**
  - Rome (Italy)
  - 3th - 4h
- **EPIPED course**
  - Girona (Spain)
  - 23th - 26th

Upcoming events

Education and Trainning

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 action toward this aim is to support EpiCARE members 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

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, Tabaee P, Alexa M, Thomschewski A, Höfler J, Rossini F, Kuchukhidze G, Kalss G, Mauritz M, Kai-Nicolas P, Toma A, Crespo B, Bosque P, Kobulashvili T, Schwimmbeck F, Trinka E.

Novel Digital Anomalies, Hippocampal Atrophy, and Mutations Expand the Genotypic and Phenotypic Spectra of CNKSR2 in the Houge Type of X-Linked Syndromic Intellectual Development Disorder (MRXSHG)

Ghasemi M, Tehrani S, Ben A, Gupta V, Stuhn I , Lesca G, Chatron N, Platzer K, Edery P, Sadeghi H, Isidor B, Cogne B, Schulz H, Krauspe I, Periyasamy R, Nampoothiri S, Mirfakhraie R, Alijanpour S, Syrbe S, Pfeifer U, Spranger S, Grundmann K, Haack T, Papadopoulou M, da Silva T, Panagiotakaki E, Arzimanoglou A, Hassan S, Rossi M, Christoph K, Lacassie Y. Mi-Hyeon J, Layman L, Miryounesi M. Hyung-Goo K

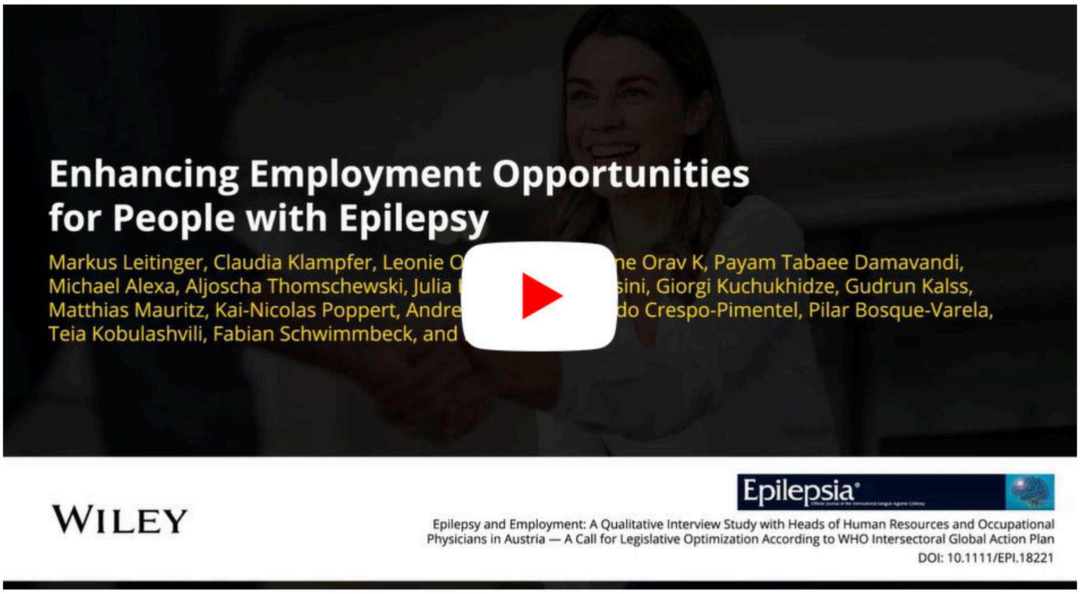
Refining management strategies for Lennox-Gastaut syndrome: Updated algorithms and practical approaches

Auvin S, Arzimanoglou A, Falip M, Striano P, Cross H

Harmonization of MRI sequences across ERN EpiCARE centers

Adler S, D'Arco F, Mankad K, Kyncl M, Arzimanoglou A, Marusic P

*We encourage all EpiCARE members to carefully read the article of **Markus Leitinger** and watch this interesting video related to this scientific publication!*



Enhancing Employment Opportunities for People with Epilepsy

Markus Leitinger, Claudia Klampfer, Leonie O ne Orav K, Payam Tabaee Damavandi,
Michael Alexa, Aljoscha Thomschewski, Julia sini, Giorgi Kuchukhidze, Gudrun Kalss,
Matthias Mauritz, Kai-Nicolas Poppert, Andre do Crespo-Pimentel, Pilar Bosque-Varela,
Teia Kobulashvili, Fabian Schwimmbeck, and

Epilepsy and Employment: A Qualitative Interview Study with Heads of Human Resources and Occupational Physicians in Austria — A Call for Legislative Optimization According to WHO Intersectoral Global Action Plan

DOI: 10.1111/EPI.18221

You can consult recent publications on rare and complex epilepsies, epilepsy surgery and other topics on our scientific publications webpage.

Please note that if you would like to contact **Nicola Lawrence** (EpiCARE CPMS & Patient Empowerment Manager), she now has a new email address: n.lawrence@epi-care.eu

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.eu

Follow us on social media!

EpiCARE
European Reference Network
Funded by the European Union