



# EpiCARE

## SUMMER 2023 NEWSLETTER

The goal of our newsletter is to keep you informed about actions related to the European Reference Network on rare and complex epilepsies, EpiCARE.

You will find information about our next events, educational and research activities and calls, but also news from the coordination team, our different members and our ePAG community.

## NEXT WEBINARS

There are no webinars in August. Let us catch up in September, with our webinars on rare and complex epilepsies every 2nd and 4th Thursday of the month!



Thursday September 7th  
17h CET

GLUT1 deficiency syndrome

Valentina De Giorgis,  
Maria Roser-Pons  
&

Monica Lucente  
(patient representative)

[Register](#)

Thursday September 21st  
17h CET

Bayesian analysis of N-of-1 trials

Victoria Defelippe,  
Wim Otte  
&

Floor Jansen

[Register](#)

You can check the programme of the upcoming webinars and register to the webinar mailing on the EpiCARE webinars webpage:

[Webinars webpage](#)

## LATEST NEWS

[EpiCARE Summer break](#)



EpiCARE will take its annual summer break in the month of August! There will be no webinars and no cases discussions.

We are still of course reachable via e-mail, and all activities are continuing. We are looking forward to September for a fresh start!

## EAN 2023



The 9th Congress of the [European Academy of Neurology](#) took place in Budapest earlier this month!

EpiCARE was well represented by both members in sessions, and part of the management team in the exhibition area.

The EpiCARE x EAN symposium on personalized medicine for the diagnosis and care

of patients with complex epilepsy syndromes, chaired by Reetta Kalviainen and Guido Rubboli, and presented by Kerstin Alexandra Klotz, Kees Braun, Simona Balestrini and Guido Rubboli, was inspiring. Missed it? You can [read a EAN page on this symposium here](#).

#### New research calls



Selected by the  
EpiCARE Research Council

Use this summer to browse the current research calls, selected by the EpiCARE Research Council!

For any question, please contact [Sébile Tchaicha](#), EpiCARE Research project manager.

Current Research calls

## EVENTS

#### International Epilepsy Congress - September 2023



**35th International  
Epilepsy Congress**  
2-6 September 2023  
Dublin, Ireland





The 35th International Epilepsy Congress is approaching!

EpiCARE will have a booth in the exhibition area, and most of our members will also be present, chairing and presenting sessions, ready to network and discuss care of rare and complex epilepsies.

For more information and registration, see the [ILAE congress website here](#).

Register now for the next Rome workshop!



## 4th Rome workshop on

# Epilepsy care challenges from neonates to adults



## December 13th to 15th, Rome, Italy

It is our pleasure to invite you to save the date of the 4th edition of the "In search of lost time" workshop, endorsed by the EpiCARE, taking place in Rome, Italy from Wednesday December 13th in the afternoon to Friday December 15th lunchtime.

This year the workshop will be on "Epilepsy care challenges from neonates to adults", a contribution to the activities of the ERN EpiCARE to translate into actions in Europe the WHO Directive on "Epilepsy and other neurological disorders".

The workshop will discuss in detail two important areas of epilepsy care:  
Neonatal seizures and epilepsies  
Epileptic Seizures in brain disorders

[REGISTRATION IS NOW OPEN!](#)



- 24-26 August: 13th ILAE School for Neuropathology and Epilepsy Surgery.
- 28 August - 1st September: XVII Workshop on Neurobiology of Epilepsy. [More info](#)
- 17-21 September: 8th Global Symposium on Ketogenic Therapies. [More info](#)

EpiCARE SCIENTIFIC PUBLICATIONS

- Aronica, E., Specchio, N., Luinburg, M. J., & Curatolo, P. (2023). Epileptogenesis in tuberous sclerosis complex-related developmental and epileptic encephalopathy. *Brain : a journal of neurology*, 146(7), 2694–2710. [Link](#)
- Auvin, S., Nortvedt, C., Fuller, D. S., & Sahebkar, F. (2023). Seizure-free days as a novel outcome in patients with Lennox-Gastaut syndrome: Post hoc analysis of patients receiving cannabidiol in two randomized controlled trials. *Epilepsia*, 64(7), 1812–1820. [Link](#)
- Casas-Alba, D., Aguilar, A., Alonso, I., García, M. T., Cilio, M. R., Fons, C., & BIO-KCNQ2-Spanish Study Group (2023). Relationship Between Epileptic Activity and Developmental Outcome in KCNQ2-Related Epilepsy. *Pediatric neurology*, 144, 11–15. [Link](#)
- Papadopoulou, M. T., Welniarz, Q., Roubertie, A., Gras, D., Milh, M., Panagiotakaki, E., & Roze, E. (2023). Effect of Oxygen Administration on Paroxysmal Motor Events in Alternating Hemiplegia of Childhood. *Movement disorders : official journal of the Movement Disorder Society*, 10.1002/mds.29561. Advance online publication. [Link](#)



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

EpiCARE members: please remember to mention EpiCARE in your affiliations or in the acknowledgements / references when appropriate.

## A word from our ePAGs

EpiCARE ePAG x EIC



**35th International Epilepsy Congress**  
2-6 September 2023  
Dublin, Ireland

The EpiCARE ePAG will be actively participating at the International Epilepsy Congress in Dublin :

- "Breakfast roundtable on rare and complex epilepsies"

As the global voice for people with epilepsy, IBE is eager to further engage with the international community of people living with rare and complex epilepsies, and those who care for them. This invite-only, multi-stakeholder roundtable will bring together epilepsy advocates, IBE chapter representatives, clinicians, researchers and companies to explore how IBE can bring added value to this space.

- Poster presentation "Patient journeys: A tool to raise awareness on the evolution, common needs, and critical issues of patients with rare and complex epilepsies."

## 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

Follow us on social media!



Our mailing address is:

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