



# EpiCARE

## MAY 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

Learn more about rare and complex epilepsies every 2nd and 4th Thursday of the month



Thursday June 15th  
17h CET

How to bridge the gap between trial  
in animals and humans

Aristea Galanopoulou &  
Jacqueline French

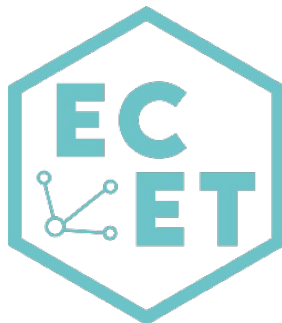
[Register](#)

Thursday June 29th  
17h CET

Does real world data provide  
enough evidence for our clinical  
practice

Vicente Villanueva &  
Stéphane Auvin

[Register](#)



These two webinars will be chaired by a member of ECET, the European Consortium for Epilepsy Trials.

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

[Webinars webpage](#)

## LATEST NEWS

### 2023 EpiCARE Annual meeting



This week was the 2023 EpiCARE Annual meeting !

75 of our members and ePAGs representatives met in Utrecht, The Netherlands to catch up on the current activities, share good practices and new input, collaborate and prepare for the new period of the ERN.

As usual, it was a great meeting with a lot of open, riveting discussions. We would like to thank all of our members for their work and dedication to helping people affected by rare and complex epilepsies. We are looking forward to the next 4 years!

### 2023 EpiCARE Nurses and EEG Technicians workshop



Following the Annual meeting, we held the first EpiCARE workshop for epilepsy nurses and EEG Technicians.

The topic was "best practices in Epilepsy Monitoring Units" and sessions included discussions on the safety in EMU, behavioral testing, stereo-EEG...

We welcome more than 65 participants from 20 different countries, all from an EpiCARE centre.

## EVENTS

### 9th Annual Congress of the European Academy of Neurology



The 9th Annual Congress of the EANeurology is taking place this July!

Find out more about the EAN2023 overarching theme "Neurology beyond the Big Data" and [register here](https://www.ean.org/congress2023).

EpiCARE will have a booth at the event, and we are looking forward to seeing you all in Budapest!

Save the date 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 Thursday 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

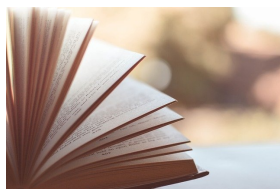
More information on registration coming soon!



- 23 February - 25 June 2023: International Online Course on Pathogenesis of Epilepsy. [More info](#)
- 20 June: EPNS Pre-congress. [More info](#)
- 20-24 June: 15th congress of the European Paediatric Neurology Society. [More info](#)
- 1-4 July: 9th Congress of the European Academy of Neurology. [More info](#)
- 17-28 July : San Servolo Epilepsy Course "Early pediatric onset epilepsies: from syndrome and management to future perspectives". [More info](#)
- 24-26 August: 13th ILAE School for Neuropathology and Epilepsy Surgery.
- 2-6 Sept : 35th International Epilepsy Congress in Dublin, Ireland. [More info](#).

## EpiCARE SCIENTIFIC PUBLICATIONS

- Astner-Rohracher, A., Mauritz, M., Leitinger, M., Rossini, F., Kalss, G., Neuray, C., Retter, E., Wortmann, S. B., Achleitner, M. T., Mayr, J. A., & Trinkla, E. (2023). A case report: New-onset refractory status epilepticus in a patient with FASTKD2-related mitochondrial disease. *Frontiers in neurology*, 13, 1063733. [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

### June awareness days




New translations, patient journeys and leaflets

We are adding new translations, patient journeys and leaflets very regularly.

Check these documents on the EpiCARE website, and do not hesitate to contact us if you are interest in providing a document for your condition, or translate an existing



one!



Read and download the following leaflets:


- **Dravet Syndrome** leaflet (B16) / Dravet syndrome Italiana (IT) / Dravet Syndrome card (B2) / Dravet Syndrome card (B4)
- **Hypothalamic Hamman-Rich syndrome** leaflet / Hypothalamic Hamman-Rich syndrome card (B16) / Hypothalamic Hamman-Rich syndrome card (B4)
- **Ring Chromosome 20** leaflet / Ring Chromosome 20 syndrome card (B16) / Ring Chromosome 20 syndrome card (B4)
- **Alarming Phenotype of Childhood** leaflet (B16) / Alarming Phenotype of Childhood card (B16) / Alarming Phenotype of Childhood card (B4)
- **GLUT1 Deficiency Syndrome** leaflet (B16) / GLUT1 Deficiency Syndrome card (B16) / GLUT1 Deficiency Syndrome card (B4)
- **CDKL5 Deficiency Disorder** leaflet (B16) / CDKL5 Deficiency Disorder card (B16) / CDKL5 Deficiency Disorder card (B4)
- **STXBP1** leaflet (B16) / STXBP1 Deficiency Syndrome card (B16) / STXBP1 Deficiency Syndrome card (B4)
- **BEFT** Syndrome leaflet (B16) / BEFT Syndrome card (B16) / BEFT Syndrome card (B4)
- **Infantile Epileptic Spikes Syndrome** (B16)

These documents are being developed progressively. New ones should be added soon.

Read and download the following patient journeys:

- **Dravet Syndrome** patient journey / Dravet Syndrome (B16)
- **Hypothalamic Hamman-Rich syndrome** patient journey / Hypothalamic Hamman-Rich syndrome (B16)
- **Alarming Phenotype of Childhood** patient journey / Alarming Phenotype of Childhood (B16) / Alarming Phenotype of Childhood (B4)
- **GLUT1** patient journey / GLUT1 Deficiency Syndrome (B16) / GLUT1 Deficiency Syndrome (B4)
- **CDKL5** patient journey / CDKL5 Deficiency Disorder (B16) / CDKL5 Deficiency Disorder (B4)
- **STXBP1** patient journey / STXBP1 Deficiency Syndrome (B16) / STXBP1 Deficiency Syndrome (B4)
- **BEFT** patient journey / BEFT Syndrome (B16) / BEFT Syndrome (B4)
- **Infantile Epileptic Spikes Syndrome** (B16)

Please note that these documents are being developed progressively. We will add more regularly.



## ePAG EpiCARE newsletter

ePAG EpiCARE is establishing a Newsletter dedicated to patients' associations dedicated to rare and complex epilepsies.

If you are a patients' association and wish to disseminate the information about your association, projects, activities and events you are planning, please contact:

[epag.epicare@gmail.com](mailto:epag.epicare@gmail.com)

If you wish to receive news from ePAG EpiCARE, [subscribe here](#).

## 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

[a.robert@epi-care.eu](mailto:a.robert@epi-care.eu)

Follow us on social media!



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