



# EpiCARE

## EpiCARE OCTOBER 2021 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.

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### NEXT WEBINAR

*Learn more every 2nd and 4th Thursday of the month with EpiCARE!*



**PCDH19-related epilepsy**

**November 11th - 17:00 CET**

**Marina Trivisano (It)  
&  
Christel Depienne (D)**

[Register now](#)

[Find the program of the next webinars on our website](#)

You can also subscribe to our **special webinars newsletter** to get a reminder a few days before each webinar.

[Subscribe to the webinars newsletter](#)

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### LATEST NEWS

[Get to know EpiCARE's coordination team](#)

We wanted to introduce again the coordination team members, so you can put a face to the person you talk to!



You already know her, but we are glad to officially re-introduce [Nicola Openshaw-Lawrence](#)! She is the **E-Learning and Data Manager (CPMS Helpdesk Coordinator)**. Her current projects include the periodic evaluation, the registry project and, of course, the webinars!

Based in London and part of the Great Ormond Street Hospital team, she has been working at EpiCARE since July 2019!

Nicola loves and tries to live by the following quote from C.S.Lewis: "*You are never too old to set another goal or to dream a new dream.*"

### Collaborative Genetic Research

One of the missions of the ERN EpiCARE is to promote clinical research and the production of cross-border collaborative work on genetic epilepsies.



To that effect, we created a [webpage](#) to share the opportunity of collaborative calls for European series of patients carrying variants in already known genes but with limited knowledge that need to be expanded.

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## EDUCATION & TRAINING

### E-learning cases

As you know, EpiCARE developed with the ILAE Academy, **patient-centred interactive e-learning modules**, corresponding to diagnosis and management of some rare and complex epilepsies (Level 2 competencies according to the ILAE curriculum).

So far, 6 cases are available on the website; you can try on these cases [here](#) and let us know what you think!

These cases were developed thanks to the CEF Telecom programme, and were co-funded by the European Agency INEA.



## ePAGs



Allison Watson, co-chair of the ePAG and Nicola Openshaw-Lawrence shared a booth at the ketogenic diet conference last week in Brighton. They appreciated the opportunity to discuss with neurologists, epilepsy specialists, nurses... and enjoyed a face-to-face meeting after too many virtual events !

## EVENTS

Save the dates - lots of interesting events to come!

- **October 28-30th:** 3rd International Congress on Mobile Devices and Seizure Detection in Epilepsy. [More info](#)
- **November 4-5th:** Eurordis all-ePAG meeting: Inspiring Collaboration and Fostering



Partnership in the ERNs.

- **December 16-18th:** EpiCARE workshop in Rome - more info to come very soon !

It will be a great occasion for EpiCARE members and stakeholders to discuss face-to-face and design EpiCARE's next 5-year plan.

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## CASE DISCUSSIONS

EpiCARE Case Discussions are scheduled every 2nd, 3rd and 4th Wednesday of the month from 4:00pm to 5:30pm CET.

Both **surgical and non-surgical cases** are discussed by panels of experts, full or affiliated members of EpiCARE. [See the agenda on our website.](#)

*To receive the link to join the case discussions, you must register. Registration is only required once to be placed on the mailing list. [Follow this link to register.](#)*

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## EpiCARE SCIENTIFIC PUBLICATIONS

- Blumcke, I., Silvia Budday, S., Poduri, A., Lal, D., Kobow, K., Baulac, S. **Neocortical development and epilepsy: insights from focal cortical dysplasia and brain tumours.** The Lancet Neurology, Volume 20, Issue 11, 2021, Pages 943-955, ISSN 1474-4422, [https://doi.org/10.1016/S1474-4422\(21\)00265-9](https://doi.org/10.1016/S1474-4422(21)00265-9).

*Written by Ingmar Blumcke, leader of the EpiCARE WP on neuropathology.*

- Cohen, N. T., Cross, J. H., Arzimanoglou, A., Berkovic, S. F., Kerrigan, J. F., Miller, I. P., Webster, E., Soeby, L., Cukiert, A., Hesdorffer, D. K., Kroner, B. L., Saper, C. B., Schulze-Bonhage, A., Gaillard, W. D., & Hypothalamic Hamartoma writing group (2021). **Hypothalamic Hamartomas: Evolving Understanding and Management.** Neurology, 10.1212/WNL.0000000000012773. Advance online publication. <https://doi.org/10.1212/WNL.0000000000012773>



Consult publications on [EpiCARE's website.](#)

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# WHAT IS NEW FOR YOU?

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

Follow us on social media !



## Our mailing address is:

Department of Paediatric Clinical Epileptology, Sleep Disorders and Functional Neurology  
ERN EpiCARE c/o Pr Arzimanoglou  
Hôpital Femme Mère Enfant (HFME)  
59 Boulevard Pinel  
69677 Bron, FRANCE

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