



EpiCARE

EpiCARE NOVEMBER 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.

NEXT WEBINAR

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



GATOR1-related epilepsy

December 9th - 17:00 CET

**Kees Braun (NL)
&
Stéphanie Baulac (FR)**

[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](#)

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 probably exchanged a lot of e-mails with [Sébile Tchaicha](#) already ! As you remember, she integrated EpiCARE at the start of 2021 as **Research project manager**.

Her favourite part of the job is to participate in the development of research projects, contributing to the link between EpiCARE and other European research networks and managing the development of the [European Collaboration for Epilepsy Trials](#) (ECET).



EpiCARE



Frequently Asked Questions

[New page on EpiCARE's website : Frequently Asked Questions !](#)

It was time to put in writing all the questions that frequently come up when EpiCARE is mentioned.

We divided the questions in 3 sections : general questions about the ERNs and EpiCARE, questions for patients, families, patients associations and questions for clinicians, healthcare professionals, specialists.

Please do not hesitate to let us know if there is anything to add, and share this page as widely as possible!

EpiCARE FAQ

EDUCATION & TRAINING

[EU Pathogenesis of epilepsy course](#)

The 2022 International 4EU+ Course on **Pathogenesis of Epilepsy** explores the **neurobiology of epilepsy from basic and clinical perspectives**. The main objectives of this course are to deepen your knowledge on the pathophysiology of epilepsy and seizure, introduce you to modern research tools that are used in epilepsy research, and identify the current challenges and complex issues in epilepsy. EpiCARE is endorsing this very interesting course.

The course is free, and starts on February 2022. [More information](#).

ePAGs

We are always seeking new patient advocacy organisations to join our **EpiCARE Patient Community**, so that we can truly represent the **wider voice of all people living with rare and complex epilepsies across Europe**.

This month we warmly welcome the following new patient representatives:

- Mr. Andrea DE COLLE from [SLC6A1 Connect Italia Ody](#)
- Mrs. Raffaella ROSSI from [Famiglie Syngap1 Italia Aps](#)
- Mrs. Alessandra COSTA from [European KCNQ2 Association](#)

If you would like to join our Patient Community and contribute to the work of ePAG EpiCARE, please send an email to: epag.epicare@gmail.com



EVENTS



IN SEARCH OF LOST TIME - 2ND EDITION

BUILDING THE EPICARE
2027 HORIZON

16TH - 18TH DECEMBER 2021
ROME, ITALY

Event organised by the Bambino Gesù Hospital team, Rome, Italy
and supported by the ERN EpiCARE



EpiCARE



Co-funded by the European Union



The second edition of the **Rome Workshop : "in search of lost time"** will take place in Rome on **December 16th-18th** ! [More information & registration](#)
Reminder: for members of EpiCARE, the registration fee is waived.

[Read the full catalogue of the programme](#)

We are looking forward to seeing everyone, and brainstorming face-to-face !



he **General Assembly** of EpiCARE will take place in Lyon, on **February 16th-18th**.

More information and official invitations will come soon, but you can save the date already !

The goal will be to reconnect, update each others on work group's progression, and hopefully integrate our new members !

EpiCARE SCIENTIFIC PUBLICATIONS

- Zhao, L., Li, J., Kälviäinen, R., Jolkkonen, J., & Zhao, C. (2021). **Impact of drug treatment and drug interactions in post-stroke epilepsy**. Pharmacology & therapeutics, 108030. Advance online publication. <https://doi.org/10.1016/j.pharmthera.2021.108030>
- Rocamora, R., Chavarría, B., Pérez, E., Pérez-Enríquez, C., Barguilla, A., Panadés-de Oliveira, L., Principe, A., & Zucca, R. (2021). **Mood Disturbances, Anxiety, and Impact on Quality of Life in Patients Admitted to Epilepsy Monitoring Units**. Frontiers in neurology, 12, 761239. <https://doi.org/10.3389/fneur.2021.761239>
- 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, 97(18), 864–873. <https://doi.org/10.1212/WNL.0000000000012773>



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

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

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
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Follow us on social media !



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