



EpiCARE

EpiCARE SEPTEMBER 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!



KCNT1-related epilepsies

September 30th - 17:00 CET

Rima Nabbout,
Giulia Barcia (F)
&
Amy McTague (UK)

[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

[Back to work!](#)

These past few weeks have been very busy, as it always is when we come back from holidays!

Lots of **events** are happening this year, and we could not be happier to get back to face-to-face meetings.

We are also **welcoming new members into EpiCARE** at the end of the year! We will keep you posted about the process and how we plan on welcoming them.

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!



As **coordination manager of EpiCARE**, [Laurène Mathey](#) helps Pr. Arzimanoglou follow the strategic topics related to the coordination of ERN at a European level. As she is the **European Affairs Manager** at the HCL, part of her duties also include following the research European projects of the hospitals, representing the ERN within the HCL, and managing the European affairs team.

Her favorite quote is on the card on her office wall : "Am Ende wird alles gut, wenn es nicht gut wird, ist es noch nicht das Ende", meaning, everything will turn out fine in the end. If it is not fine, it is not the end!

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).

We are glad to inform you that the **6th case, on Hypothalamic Hamartomas**, is online! [Check it out now](#) 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



A new website has been created in Italia, regarding **Rare Epilepsies Alliance**, the [Alleanza Epilessie Rare e Complesse](#).

We can congratulate Isabella Brambilla for this initiative, of which the goal is to have a **common voice** in raising awareness of rare diseases and epilepsies.



The **Hope for Hypothalamic Hamartomas website** has been completely revamped!

The website promotes research into early detection, improved treatments, living with HH as a complex medical syndrome, and a cure. [Have a look here](#).

EVENTS



Save the dates - lots of interesting events to come!

- **October 6th** : EPICLUSTER - Accelerating Patient Involvement in European Epilepsy Research - [More info](#).
- **October 12th** : European Brain Summit - [More info](#).
- **October 17-19th** : 7th global symposium ketogenic dietary therapies - [More info](#).
- **October 28-30th** : 3rd International Congress on Mobile Devices and Seizure Detection in Epilepsy - [More info](#).

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.](#)

EpiCARE SCIENTIFIC PUBLICATIONS

- Bjellvi, J., Cross, J. H., Gogou, M., Leclercq, M., Rheims, S., Ryvlin, P., Sperling, M. R., Rydenhag, B., & Malmgren, K. (2021). **Classification of complications of epilepsy surgery and invasive diagnostic procedures: A proposed protocol and feasibility study.** *Epilepsia*, 10.1111/epi.17040. Advance online publication. <https://doi.org/10.1111/epi.17040>
- Arzimanoglou, A., Pringsheim, M., Kluger, G. J., Genton, P., Perdomo, C., & Malhotra, M. (2021). **Safety and efficacy of rufinamide in children and adults with Lennox-Gastaut syndrome: A post hoc analysis from Study 022.** *Epilepsy & behavior : E&B*, 124, 108275. Advance online publication. <https://doi.org/10.1016/j.yebeh.2021.108275>
- Linehan, C., Benson, A., Gunko, A., Christensen, J., Sun, Y., Tomson, T., Marson, A., Forsgren, L., Trinkka, E., Iliescu, C., Althoehn Sonderup, J., Werenberg Dreier, J., Sandu, C., Leanca, M., Rainer, L., Kobulashvili, T., Granbichler, C. A., Delanty, N., Doherty, C., Staines, A., ... ESBAACE Consortium and Collaborators (2021). **Exploring the prevalence and profile of epilepsy across Europe using a standard retrospective chart review: Challenges and opportunities.** *Epilepsia*, 10.1111/epi.17057. Advance online publication. <https://doi.org/10.1111/epi.17057>



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

MISCELLANEOUS

[Sándor Beniczky](#), member of EpiCARE from Aarhus (Denmark), is working on a study about the **efficacy and use of wearable seizure detection devices**.

To help advance the study, you can **answer this quick questionnaire** - link below - and forward it to patients with tonic-clonic seizure (or their carers) who use this kind of device.

To learn more about the study, you can watch [Torie Robinson's latest interview of Prof. Beniczky](#).

Questionnaire

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.robert@epi-care.eu

Follow us on social media !



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