



EpiCARE

EpiCARE FEBRUARY 2022 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!



Recognition of MOGHE and it's differential diagnosis with FCD type I

March 10th at 17:00 CET

Till Hartlieb
&
Hans Holthausen

Register now

Subscribe to the [webinars mailing](#) to get a reminder a few days before each webinar.

[Subscribe to the webinars newsletter](#)

LATEST NEWS

[EpiCARE fifth annual meeting](#)



The 5th Annual meeting was a success! We were glad to be able to meet in person after so many visioconferences. The goal of these 2 days was to report on the past 5 years actions, and build from there a solid plan for the next 18-months period. We were also glad to welcome our new members, integrated into the ERN this January!

Building on the previous period's report, 4 priorities were identified for the next one:

- Strengthen the links between EpiCARE and reference networks for rare epilepsies as well as patient associations active at national level
- Pursue all previously developed scientific activities and care initiatives to improve healthcare management of patients with rare and complex epilepsies and enhance knowledge generation
- Populate the EpiCARE registry with accurate and expert-validated data
- Foster the conditions for better clinical trials and innovative research in epilepsy

A word from our ePAGs



It was exciting and hugely beneficial for ePAG representatives to once again be a part of the **EpiCARE Annual Meeting** in Lyon, both in-person and online. The last five years have been extraordinary in many ways, a strong network has been created, professional friendships have been made and strengthened, complex epilepsy cases have been reviewed and given the benefit of considered expert advice. There is every reason to hope and to believe that the continued productivity and generosity in the pooling of ideas and resources will lead to significant and tangible improvements over the next five years for those living with rare and complex epilepsies.

We, the ePAGs, have actively participated in every workshop, **bringing the patient perspective into the planning**, and sought to embed key ePAG initiatives firmly within

the Working Group deliverables.

We presented our main goal for the next 18 months interim period of EpiCARE which is to **further develop our Patient Community** to start to build a network covering as many rare epilepsies, across as many European countries as possible. We aim to **build a directory of rare epilepsy patient organisations/representatives** (to be listed on the EpiCARE website) both to signpost families for support but also who we can call upon to contribute to specific EpiCARE projects where specific experience and expertise are required.

Call for new ePAG EpiCARE members

Our initial objective is to **identify one patient representative, per country** who can act as a liaison within their own local community, therefore overcoming barriers of translation. **Can you help us by suggesting an English-speaking patient representative for your country?** If so, please tell them to contact us at: epag.epicare@gmail.com to discuss further. We look forward to hearing from you.

EVENTS

Lots of interesting events coming up!



- Today is [Rare Disease day](#)! Join the event on social media to raise Rare diseases awareness
- 26 March: Purple Day - show your support for epilepsy awareness by wearing purple. [More info](#)
- 17-19 March: 48th meeting of the European Society of Pediatric Neurology. [More info](#) (french)
- 19 March: KCNB1 2nd international conference for Families, Doctors and Researchers. [More info](#)
- 20-25 March: ILAE Training Course in Neuropsychology in Epilepsy. [More info](#)

EpiCARE SCIENTIFIC PUBLICATIONS

- Barba, C., Rheims, S., Minotti, L., Grisotto, L., Chabardès, S., Guenot, M., Isnard, J., Pellacani, S., Hermier, M., Ryvlin, P., & Kahane, P. (2022). **Surgical outcome of temporal plus epilepsy is improved by multilobar resection.** *Epilepsia*, 10.1111/epi.17185. Advance online publication. <https://doi.org/10.1111/epi.17185>



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

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](#).

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 !



Co-funded by
the European Union

Our mailing address is:

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