



EpiCARE

DECEMBER 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

Our webinars on rare and complex epilepsies take place every 2nd and 4th Thursday of the month, and the replays are always available on our website.

Thursday December 21st - 17h CET

Tools developed by patient organisations for improving physician-patient communication - an ePAG Webinar

Isabella Brambilla, Andrea Lodi

&

Irena Bibic

[Register here](#)

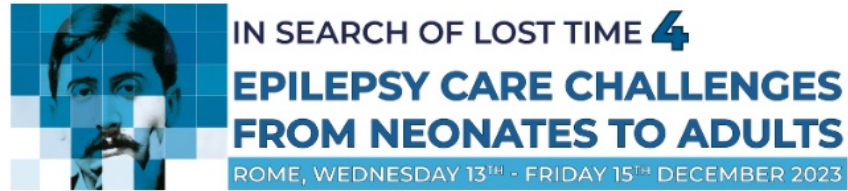


You can check the programme of the upcoming webinars and register to the webinar mailing on the EpiCARE webinars webpage:

[Webinars webpage](#)

LATEST NEWS

4th edition of the Rome workshop "in search of lost time"



Once again, the Rome workshop "in search of lost time" was a success! The focus this year was on epilepsy care challenges, from neonate to adults.

Hosted by the Bambino Gesù team and endorsed by EpiCARE, this now traditional event is a great opportunity for epilepsy experts to touch base at the end of the year, share their work, discuss hot topics, network and collaborate.

Consortium éPiRaReS



The [éPiRaRes Consortium](#) (University Hospital Robert Debré, University Hospital Salêtrière and Rothschild foundation, Paris), full member of EpiCARE, held his second symposium last month in Paris. Each hospital composing the consortium presented two scientific topics relating to its news or activities, making for a very interesting programme on rare epilepsies.

Best wishes for the end of the year



EDUCATION & TRAINING

[EpiCARE neuroimaging workshops on replay](#)

In 2022 – 2023, the EpiCARE Neuroimaging work group, led by Prof. Marusic from Motol University Hospital (Prague, Czech Republic) and by Dr. Sophie Adler, from UCL (London, UK), organised 3 neuroimaging workshops on the MELD project (Multi-centre Epilepsy Lesion Detection), PET and MAP.

We are glad to share the replays of these workshops on our website.

[Neuroimaging workshops replays](#)

EVENTS

[Symposium on paediatric movement disorders / Feb 8-10](#)



The aim of this event is to pursue the collaborative activities among professionals interested in paediatric movement disorders successfully started in the Symposium 2004. As in the previous meetings, the best qualified experts involved in paediatric movement disorders will take part in this Symposium.

[More information and registration](#)

[EPIPED Course / April 10-13](#)



The aim of the 3-year cycle EPIPED-Treatment is to reduce the geographical and knowledge gap by providing neurologists and child neurologists involved in epilepsy care the opportunity for a regular update on best treatment practices. The concept of EPIPED is based on a 3-year cycle of independent annual training courses, developed specifically for child neurologists, physicians and epilepsy nurses caring for patients with epilepsy.

[More information and registration](#)

Paros Epilepsy / April 22-26



Epilepsy surgery has been relying on anatomo-clinical correlation for more than a century and much knowledge has been accumulated over decades, in particular since the advances of long-term video-EEG monitoring. With the more recent worldwide deployment of SEEG, fine correlations have further progressed, as well as our understanding of their potential bias, ambiguities and limitations.

We believe that a comprehensive systematic assessment of these anatomo-clinical correlations is much needed, and have thus organized this endeavour with the joint endorsement support of the European Reference Network EpiCARE, ILAE-Europe and the ILAE educational journal Epileptic Disorders.

[See the full programme of the event here.](#)

The meeting itself will take place in a unique and magnificent venue in the Greek Cyclades, thanks to the support of the Greek League Against Epilepsy.

We anticipate to share a wonderful, intellectually exciting and memorable moment, that shall provide a landmark in clinical epileptology.

We thus hope to see you there!

The organizing committee

Alexis Arzimanoglou, Sandor Beniczky, Philippe Kahane, Vasilis Kimiskidis and Philippe Ryvlin.

[More information and registration](#)

EpiCARE SCIENTIFIC PUBLICATIONS

- Rinaldi, B., Bayat, A., Zachariassen, L. G., Sun, J. H., Ge, Y. H., Zhao, D., Bonde, K., Madsen, L. H., Awad, I. A. A., Bagiran, D., Sbeih, A., Shah, S. M., El-Sayed, S., Lyngby, S. M., Pedersen, M. G., Stenum-Berg, C., Walker, L. C., Krey, I., Delahaye-Duriez, A., Emrick, L. T., ... Kristensen, A. S. (2023). Gain-of-function and loss-of-function variants in GRIA3 lead to distinct neurodevelopmental phenotypes. *Brain : a journal of neurology*, awad403. Advance online publication. [Link](#)
- Honke, J., Hoffmann, L., Coras, R., Kobow, K., Leu, C., Pieper, T., Hartlieb, T., Bien, C. G., Woermann, F., Cloppenborg, T., Kalbhenn, T., Gaballa, A., Hamer, H., Brandner, S., Rössler, K., Dörfler, A., Rampp, S., Lemke, J. R., Baldassari, S., Baulac, S., ... Blümcke, I. (2023). Deep histopathology genotype-phenotype analysis of focal cortical dysplasia

type II differentiates between the GATOR1-altered autophagocytic subtype IIa and MTOR-altered migration deficient subtype IIb. Acta neuropathologica communications, 11(1), 179. [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

[Awareness days](#)



**LIVING
WITH
AHC**

TOGETHER, WE CAN MAKE A DIFFERENCE
JOIN US IN RAISING AWARENESS FOR
ALTERNATING HEMIPLEGIA OF CHILDHOOD

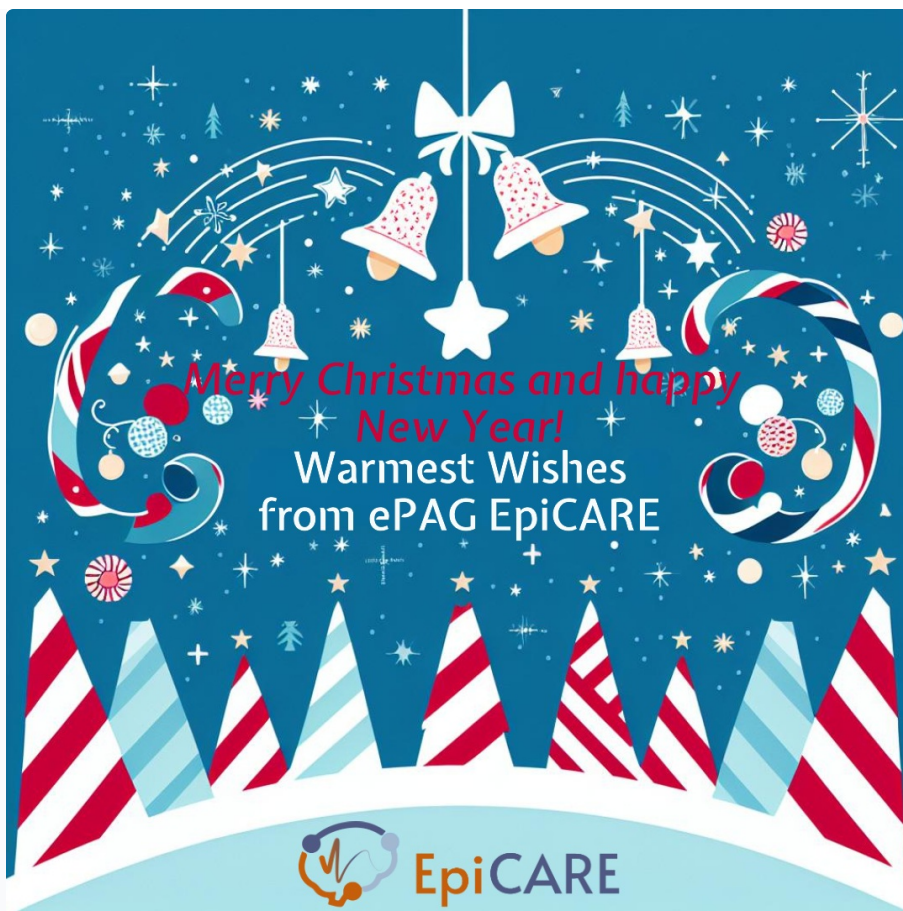
Rome workshop In search of lost time: Epilepsy care challenges from neonates to adults



Workshop In search of lost time was held in Rome, from December 13th to 15th. During the workshop, our ePAGs have led a session: Epileptic Seizures in neurological disorders: the role of Patient Advocates.

Carol-Anne Partridge has talked about pharmacological therapies and its impact on daily life, Rosaria Vavassori raised the issue of neurological and neuropsychological comorbidities, and Maryse Arendt wrapped up the session with the importance and necessity of multidisciplinary and holistic approach.

We thank all the participants for taking their time in answering our question about the therapy and its side effects and the multidisciplinary care, and for raising a great discussion!



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 info@epi-care.eu

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