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EpiCARE

January 2024 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

Our webinars on rare and complex epilepsies take place once a month, and the replays are always available on our website.

Thursday February 22nd - 17h CET

Routine and Sleep EEG: Minimum recording standards of the International Federation of Clinical Neurophysiology and the ILAE

Presented by: Maria Peltola

[Register here](#)



EpiCARE

**Educational
webinars**

Free to access

Registration necessary

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

LATEST NEWS

Change of EpiCARE Coordination Centre



On October 1st, 2023 ERN EpiCARE coordination moved from Hospices Civils De Lyon, in France to Hospital Sant Joan de Deu in Barcelona, Spain, with Prof. Alexis Arzimanoglou continuing as coordinator.

We are confident that Hospital Sant Joan de Deu will effectively manage and steer ERN EpiCARE towards further success. Their dedication and commitment to improving the quality of care, advancing research, and fostering collaboration align perfectly with the network's goals and vision.

Meet our new Financial and Administrative Manager

Belén Trebino Harrington

Belén joined the management team in October 2023. She will be responsible for monitoring the EpiCARE budget; will participate in co-financing contracts and other EU4Health Projects, and be a liaison for the overall coordination. She has a degree in business administration with a specialization in project management, and has extensive experience in the field of international public healthcare management.



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

International Epilepsy Day - 12th February 2024



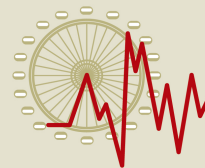
International Epilepsy Day

This global initiative aims to raise awareness about epilepsy and advocate for the rights of people with epilepsy worldwide.

International Epilepsy Day serves as an opportunity for individuals, organisations, and communities around the world to unite and shine a light on epilepsy. By coming together, we can help break the stigma surrounding epilepsy, promote understanding, and support those living with the condition.

For more information visit the [IBE International Epilepsy Day Toolkit](#)

9th London-Innsbruck Colloquium on Status Epilepticus and Acute Seizures



**9TH LONDON-INNSBRUCK
COLLOQUIUM
ON STATUS EPILEPTICUS
AND ACUTE SEIZURES**

**APRIL 8 – 10, 2024
LONDON, UK**

This meeting has been held every two years since 2007 and has become a landmark meeting in the international epilepsy calendar.

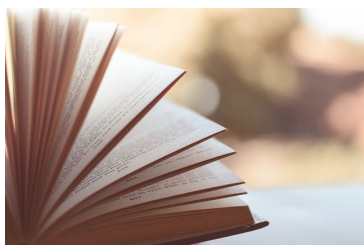
The faculty includes the leading figures in the field of *Status Epilepticus and Acute Seizures* from around the world.

The meeting will be held in a hybrid format for the first time allowing people to join online, with all course material being made available to registrants for one month after the colloquium completion.

[More information and registration](#)

EpiCARE SCIENTIFIC PUBLICATIONS

- de Nys R, van Eyk CL, Ritchie T, Møller RS, Scheffer IE, Marini C, Bhattacharjee R, Kumar R, Gecz J. **Multimic analysis implicates nuclear hormone receptor signalling in clustering epilepsy.** Transl Psychiatry. 2024 Jan 27;14(1):65. doi: 10.1038/s41398-024-02783-5. PMID: 38280856. [Link](#)
- Cavirani B, Spagnoli C, Caraffi SG, Cavalli A, Cesaroni CA, Cutillo G, De Giorgis V, Frattini D, Marchetti GB, Masnada S, et al. **Genetic Epilepsies and Developmental Epileptic Encephalopathies with Early Onset: A Multicenter Study.** International Journal of Molecular Sciences. 2024; 25(2):1248. doi: 10.3390/ijms25021248. [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

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



On December 21st, ePAG EpiCARE held a webinar about tools developed by patient organisations for improving the communication between patients/caregivers and physicians.

Isabella Brambilla presented the Dravet Diary, Andrea Lodi, president of Associazione Italiana Glut1, presented KETONET, an app developed by the association and associates and Irena Bibić presented Dravet Emergency protocol, a project initially developed by Dravet Syndrome European

Federation's Scientific Advisory Board and patient representatives, and currently endorsed by EpiCARE ERN.

The webinar is available to view at: <https://epi-care.eu/past-webinars/>

Save the date for the European Dravet Syndrome Conference 2024

Fundación Síndrome de Dravet is organising a Dravet syndrome conference in 2024. Save 14th and 15th of March 2024 in your calendars and join the conference in Madrid.

[For preliminary program and registration, click here.](#)



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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