



EpiCARE

NOVEMBER 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

[Register here](#)



Free to access

Registration necessary

**Educational
webinars**

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

[Webinars webpage](#)

[See the new ERNs brochure here.](#)

MetabERN Questionnaire on the Treatment of Primary Mitochondrial Disorders with Vitamins and Cofactors

Primary mitochondrial disorders (PMD) continue to be without any curative or evidence-based therapies, but in many cases, clinicians use one or more vitamins or cofactors to support the patient's mitochondrial function/metabolism and thereby help to alleviate the patient's health complaints.

In order to improve our understanding of which vitamins and cofactors clinicians use to support patients with PMD, the MetabERN's Pyruvate metabolism mitochondrial oxidative phosphorylation disorders, Krebs cycle defects, disorders of thiamine transport and metabolism subnetwork [PM-MD (Mito)] has prepared a questionnaire. The aims of this survey are:

- to map the daily practice of vitamin and cofactor use among physicians treating children and adults affected by PMD
- to use information from the survey to begin to develop recommendations for the use of vitamins and cofactors to support patients affected by PMD

The questionnaire is open to all PMD specialists from around the world until December 31, 2023. Answering takes 15-20 minutes. Please share this questionnaire with your colleagues in other centers/countries! [Start answering the questionnaire](#).

Thank you for your cooperation!

kind regards,

Karit Reinson, Shamima Rahman, Manuel Schiff and Enrico Berini

On behalf of the MetabERN European Reference Network

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](#)

EURONDD Event - call for posters / April 4-5



This Workshop offers perspectives from different disciplines such as geneticists, pediatricians, neurologists, psychiatrists and all other specialists involved in care and scientists in basic and translational research involving patients with rare genetic neurodevelopmental disorders.

Call for poster - deadline November 30th. [More information.](#)

[More information and registration](#)

EIPED Course / April 10-13



The aim of the 3-year cycle EIPED-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 EIPED 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!

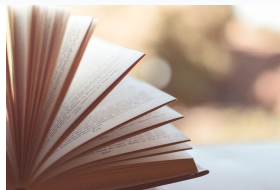
The organizing committee

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

[More information and registration](#)

EpiCARE SCIENTIFIC PUBLICATIONS

- Kuchenbuch, M., Lo Barco, T., Chemaly, N., Chiron, C., & Nabbout, R. (2023). 15 years of real-world data on the use of vigabatrin in individuals with infantile epileptic spasm syndrome. *Epilepsia*, 10.1111/epi.17808. [Link](#)
- Orav, K., Bosque Varela, P., Prüwasser, T., Machegger, L., Leitinger, M., Trink, E., & Kuchukhidze, G. (2023). Post-hypoxic status epilepticus - A distinct subtype of status epilepticus with poor prognosis. *Epileptic disorders : international epilepsy journal with videotape*, 10.1002/epd2.20164. Advance online publication. [Link](#)
- Rainer, L. J., Kuchukhidze, G., Trink, E., Braun, M., Kronbichler, M., Langthaler, P., Zimmermann, G., Kronbichler, L., Said-Yürekli, S., Kirschner, M., Zamarian, L., Schmid, E., Jokeit, H., & Höfler, J. (2023). Recognition and perception of emotions in juvenile myoclonic epilepsy. *Epilepsia*, 10.1111/epi.17783. Advance online publication. [Link](#)
- Beuchat, I., Novy, J., Rosenow, F., Kellinghaus, C., Rüegg, S., Tilz, C., Trink, E., Unterberger, I., Uzelac, Z., Strzelczyk, A., & Rossetti, A. O. (2023). Staged treatment response in Status epilepticus - Lessons from the SENSE registry. *Epilepsia*, 10.1111/epi.17817. [Link](#)
- Krey, I., Platzer, K., Esterhuizen, A., Berkovic, S. F., Helbig, I., Hildebrand, M. S., Lerche, H., Lowenstein, D., Möller, R. S., Poduri, A., Sadleir, L., Sisodiya, S. M., Weckhuysen, S., Wilmschurst, J. M., Weber, Y., Lemke, J. R., Berkovic, S. F., Cross, J. H., Helbig, I., Lerche, H., ... Weckhuysen, S. (2022). Current practice in diagnostic genetic testing of the epilepsies. *Current practice in diagnostic genetic testing of the epilepsies. Epileptic disorders : international epilepsy journal with videotape*, 24 (5), 765–786. [Link](#)
- Vorndran, J., Neuner, C., Coras, R. et al. A deep learning-based histopathology classifier for Focal Cortical Dysplasia. *Neural Comput & Applic* 35, 12775–12792 (2023). [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](#)



LET'S MAKE A DIFFERENCE TOGETHER

JOIN US IN RAISING
AWARENESS



International
Day of
**Persons with
Disabilities**

3 DECEMBER

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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