



# EpiCARE

## OCTOBER 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 November 2nd  
17h CET

Design for and analysis of trials for  
small sample size

Ralf Dieter  
&  
Rima Nabbout

[Register](#)

Thursday November 16th  
17h CET

Metabolic etiology of West  
syndrome

Solomon Moshe  
&  
Aristea Galanopoulou

[Register](#)



**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:

[Webinars webpage](#)

## LATEST NEWS

[Session for young members at the Rome workshop!](#)



## IN SEARCH OF LOST TIME **4**

# EPILEPSY CARE CHALLENGES FROM NEONATES TO ADULTS

ROME, WEDNESDAY 13<sup>th</sup> - FRIDAY 15<sup>th</sup> DECEMBER 2023

Young participants < 40 at the moment of submission are invited to send an abstract (free Topic) that will be considered for oral session "Fostering the future" on December 15th.

The selected 10 authors will receive free registration to the Workshop.

Check out the [workshop's website](#) for abstracts requirements and structure.

Contributions will be evaluated by the Scientific Committee and confirmation of acceptance will be sent on November 23rd by e-mail.

Do not miss the opportunity to share your contribution during "IN SEARCH OF LOST TIME 4 WORKSHOP"

### Guidelines International Network



The EpiCARE Guidelines group is currently working on 7 task forces (Lennox Gastaut Syndrome, Infantile Epileptic Spasms, Dravet Syndrome, Status Epilepticus, Epilepsy Surgery (Presurgical Evaluation, Epilepsy Surgery and Neuromodulation) and have already finalized three protocols.

They have established working groups and have strengthened the collaboration between four involved societies (EAN, ILAE, EPNS and EpiCARE) so far.

They also strengthened the guideline network collaboration to other societies around the world and had the chance to meet and learn from experts for guideline development.

Pictured here at the Guidelines International Network: Martin Geroldinger and Teia Kobulashvili from EpiCARE, and Katina Aleksovska and Abigail Magno from EAN.

### Feedback on the LAFORA events



Last month, a major event on Lafora was hosted in Bologna, Italy, consisting of the international symposium and the Italian group workshop, both patroned by EpiCARE.

Photo : Bringing together global experts in Bologna, Italy, to advance research on Lafora disease at two successful events under the auspices of EpiCARE, the international Lafora symposium and the workshop on the project DEFEAT-LD

## EVENTS

### DEE clinical case discussion (Italian) - November 17th

3 Italian EpiCARE centres, Fondazione Mondino, Università di Pavia, Università degli studi di Brescia and the IRCCS Carlo Besta, are organising a discussion of clinical cases of difficult management on developmental and epileptic encephalopathies.

The discussions, in Italian only, will feature a number of great speakers, experts on the topic.

[Learn more and register here.](#)

### Programme of the 2024 Rome workshop

It is our pleasure to invite you to register for the 4th edition of the "In search of lost time" workshop, endorsed by the EpiCARE, taking place in Rome, Italy from Wednesday December 13th in the afternoon to Friday December 15th lunchtime. This year the workshop will be on "Epilepsy care challenges from neonates to adults",

[See the detailed programme and the list of speakers here.](#)

Registration & more information

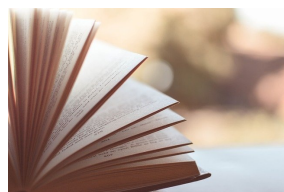
- Oct. 27-28: 11th Symposium ATP1A3 in Disease. [More info](#)
- Nov 6: Rare and Complex Epilepsy Academy RCEA III (German). [More info](#)



- Nov. 10-12: Comprehensive Update on Refractory Epilepsy (CURE). [More info](#)
- Nov. 17: Dravet Syndrome UK Parent/Carer Conference. [More info](#)
- Nov. 18: Dravet Syndrome UK Professionals Conference. [More info](#)

## EpiCARE SCIENTIFIC PUBLICATIONS

- Mancuso, M., Lopriore, P., Lamperti, C., Klopstock, T., Rahman, S., Licchetta, L., Kornblum, C., Wortmann, S. B., Dollfus, H., Papadopoulou, M. T., Arzimanoglou, A., Scarpa, M., Graessner, H., & Evangelista, T. (2023). Current management of primary mitochondrial disorders in EU countries: the European Reference Networks survey. *Journal of neurology*, 10.1007/s00415-023-12017-1. [Link](#)
- 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](#)



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

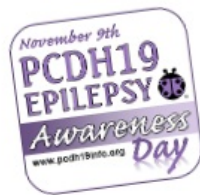
[Awareness days](#)

# JOIN US IN RAISING AWARENESS

LGS  
Nov 1st



Ohtahara  
Nov 15th



PCDH19  
Nov 9th

Together we can make  
a difference

## 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  
[a.robert@epi-care.eu](mailto:a.robert@epi-care.eu)

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