



EpiCARE

March 2024 NEWSLETTER

If you want to be informed about our next events, educational and research activities and calls, but also news from the coordination team, our different members and our ePAG community...don't miss this **Newsletter!**

Feel free if you want to **forward** this newsletter... and here is the [link to sign up](#) and receive it every month!

NEXT WEBINAR

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

Thursday April 18th - 17h CET

Systematic autoimmune disorders and epilepsy

Presented by: Claude Steriade and Roland Thijs

[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

Jardin project meeting in Brussels



On 8 March, the JARDIN (**Joint Action on integration of ERNs into national healthcare systems**) project meeting was held in Brussels. The conference showcased a strong, united commitment from EU institutions, Member States, EURORDIS, and the broader patient advocate community towards **integrating ERNs into national healthcare systems** and **advancing EU rare disease policies**. Many stakeholders were present, interesting discussions were held on a challenging project designed to serve patients with rare diseases. Thanks to HADEA for organising and hosting the meeting, Till Voigtlaender for coordinating JARDIN, DG SANTE, ERN coordinators, patient representatives, representatives of the Board of Member States and all others for their commitment.



"Managing Epilepsies in Crisis Situations - The Ukraine Experience"

On 21 March, ERN EpiCARE had the honour to welcome two eminent colleagues, also members of the Ukrainian chapter of the International **League Against Epilepsy**, Professors **Andriy Dubenko** and **Volodymyr Kharytonov**. They shared with us their experience during these 2 years of war, in an educational webinar on "Managing Epilepsies in Crisis Situations - The Ukraine Experience".

The webinar was moderated by Professors **Maša Malenica** and **Alexis Arzimanoglou**. They both renewed the full support of EpiCARE to patients and colleagues from Ukraine, in sharing expertise and for orienting patients, particularly war refugees with rare epilepsies, towards reference centres in Europe.

Here you have the [link to the recording](#).



Meet our new Communication manager: Laura Roig Casanovas

Laura joined the management team in March 2024. She will be the strategic planner and executor of Communication, based in Hospital Sant Joan de Déu. Laura has a degree in Journalism with a Master MBA, and has experience as a communications consultant and copywriter. In EpiCARE, she will be responsible for communication, dissemination, social networks, website and content creation, among other tasks.

EVENTS

APRIL

Treatment Strategies in Pediatric Epilepsies (EPIPED) - Girona, Spain. Dates: 10 – 13 april

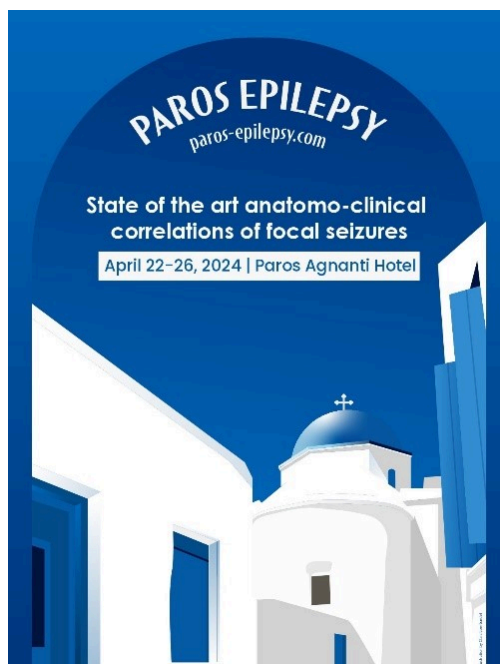


EPIPED is a 3 years cycle of independent annual training courses (2017-2019), **developed specifically for child neurologists and physicians treating children with epilepsy**, particularly rare and complex epilepsies. **Victoria San Antonio, Jaume Campistol, Alexis Arzimanoglou** are the Course Directors.

Topics treated are related to pharmacology, pharmacodynamics, pharmacokinetics, analysis of AED trials, design of clinical trials, pre-surgical evaluation, optimal choice of AEDs, review of existing guidelines (ILAE, NICE, other), ketogenic diet, neurostimulation, indications for resective and palliative surgery, pharmacological treatments other than AEDs, development of educational therapy programs.

The registration is now **close** because the course is full, but there is [more information here](#).

State of the art anatomo-clinical correlations of focal seizures. 17th Paros Epilepsy Surgery Workshop and U-Tas Meeting - Paros, Greece. Dates: 22– 26 april.



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.

The comprehensive systematic assessment of these anatomo-clinical correlations is much needed, and have thus organized these **sessions** with the joint endorsement support of the European Reference Network EpiCARE, ILAE-Europe and the ILAE educational journal Epileptic Disorders. **Alexis Arzimanoglou, Sandor Beniczky, Philippe Kahane, Vasilis Kimiskidis and Philippe Ryvlin** are the organizing committee of this event.

[Here for more information and for the registration for virtual attendazce.](#)

MAY

		1	2	3	4	5 17th ELIAT Congress on New Antiseizure Medications (Madrid)
6 17th ELIAT Congress on New Antiseizure Medications (Madrid) / 18th ICNA International Child Neurology Congress (Capetown, Southafrica)	7 17th ELIAT Congress on New Antiseizure Medications (Madrid) / 18th ICNA International Child Neurology Congress (Capetown, Southafrica)	8 17th ELIAT Congress on New Antiseizure Medications (Madrid) / 18th ICNA International Child Neurology Congress (Capetown, Southafrica)	9 17th ELIAT Congress on New Antiseizure Medications (Madrid) / 18th ICNA International Child Neurology Congress (Capetown, Southafrica)	10 18th ICNA International Child Neurology Congress (Capetown, Southafrica)	11	12
13	14	15 12th European Conference on Rare Diseases & Orphan Products (ECRD 2024) EURORDIS (Brussels, Belgium)	16 12th European Conference on Rare Diseases & Orphan Products (ECRD 2024) EURORDIS (Brussels, Belgium)	17 12th European Conference on Rare Diseases & Orphan Products (ECRD 2024) EURORDIS (Brussels, Belgium)	18	19
20	21 Tagliacozzo Trainging Course (Rome, Italy) / 20th Meeting of the ERNs Coordinations Group (Luxembourg)	22 Tagliacozzo Trainging Course (Rome, Italy) / 20th Meeting of the ERNs Coordinations Group (Luxembourg)	23 Tagliacozzo Trainging Course (Rome, Italy)	24 Tagliacozzo Trainging Course (Rome, Italy)	25 Tagliacozzo Trainging Course (Rome, Italy)	26
27	28	29	30	31		

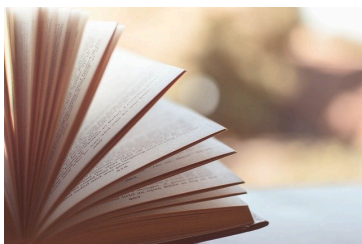
In addition, we would like to share with you the links with more information about this events:

[17th ELIAT Congress on New Antisezure Medications](#)
[18th ICNA Internacional Child Neurology Congress](#)
[12h European Conference on Rare Diseases & Orphan Products EURODIS](#)
[Tagliacozzo Training Course](#)

In the April newsletter, we will give full details of events in May!

EpiCARE SCIENTIFIC PUBLICATIONS

- Papadopoulou M, Muccioli L, Bisulli F, Klotz KA, FonsC, Trivisano M, Kabulashvili T, Specchio N, Lesca G, Arzimanoglou A. **Accessibility, availability, and common practices regarding genetic testing for epilepsy across Europe: A survey of the European Reference Network EpiCARE**. *Epilepsia Open*. 2024 Mar 22. [LINK](#)
- Mancuso M, Lopriore P, Lamperti C, Klopstock T, Rahman S, Licchetta L, Kornblum C, Wortmann SB, Dollfus H, Papadopoulou MT, Arzimanoglou A, Scarpa M, Graessner H, Evangelista T. **Current management of primary mitochondrial disorders in EU countries: the European Reference Networks survey**. *J Neurol*. 2024;271(2):835-840. [LINK](#).
- Amin S, Møller RS, Aledo-Serrano A, Arzimanoglou A, Bager P, Józwiak S, et al. **Providing quality care for people with CDKL5 deficiency disorder: A European expert panel opinion on the patient journey**. *Epilepsia Open*. 2024 Mar 7. DOI: [LINK](#)
- Ryvlin P, Barba C, Bartolomei F, et al. **Grading system for assessing the confidence in the epileptogenic zone reported in published studies: A Delphi consensus study**. *Epilepsia*. Published online February 29, 2024. [LINK](#)
- van Arnhem MML, van den Munckhof B, Arzimanoglou A, et al. **Corticosteroids versus clobazam for treatment of children with epileptic encephalopathy with spike-wave activation in sleep (RESCUE ESES): a multicentre randomised controlled trial**. *Lancet Neurol*. 2024;23(2):147-156. [LINK](#)
- Sanders MW, Van der Wolf I, Jansen FE, et al. **Outcome of Epilepsy Surgery in MRI-Negative Patients Without Histopathologic Abnormalities in the Resected Tissue**. *Neurology*. 2024;102(4):e208007. [LINK](#)
- Auvin S, Guillo S, de Rycke Y, Tran D, Tubach F. **Benzodiazepines for pediatric epilepsies and their risks in a cohort within the French health care data**. *Epilepsia*. Published online February 14, 2024. [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

Rare disease day

Living with epilepsy is challenging, but facing a rare form can present even more hurdles. Today we distinguish **more than 130 rare and complex epilepsies!** Let's raise awareness, spread understanding, and support those who fight these lesser-known battles every day. Together, we can make a difference in their lives. Have a look at our Awareness video [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

Follow us on social media!



**European
Reference
Network**
for rare or low prevalence
complex diseases

⚙ **Network**
Epilepsies (ERN EpiCARE)

● **Coordinator**
Hospital Sant Joan de Déu
— Spain

Co-funded by the European Union



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