



EpiCARE

JUNE 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

Learn more about rare and complex epilepsies every 2nd and 4th Thursday of the month



Thursday June 29th
17h CET

Does real world data provide
enough evidence for our clinical
practice?

Vicente Villanueva & Stéphane
Auvin

[Register](#)

Thursday July 13th
17h CET

Cerebral folate deficiency

Maria Papadopoulou & Marie-Cécile
Nassogne

[Register](#)

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

[Webinars webpage](#)

LATEST NEWS

[EPNS](#)



last week was the 15th Congress of the [European Paediatric Neurology Society \(EPNS\)](#) in Prague.

EpiCARE shared a booth with the other neurological ERNs : [MetabERN](#), [ITHACA](#) and [Euro-NMD](#), and we had a common symposium on rare neurological disorders and the role of the European Reference Networks.

It was a great opportunity to exchange with our ERN Colleagues, see EpiCARE members and inform neurologists about the activities of our 4 networks. We really appreciated this congress and thank the EPNS and Intercongress DE for a great time!

Calls for collaborative genetic research



One of the missions of the ERN EpiCARE is to promote clinical research and the production of cross-border collaborative work on genetic epilepsies.

On our website, we share the opportunities of collaborative calls for European series of patients carrying variants in already known genes but with limited knowledge that need to be expanded.

EpiCARE can facilitate this type of studies by connecting several centers across Europe involved in the study of genetic epilepsies.

We currently have calls for the following genes : GRIA, KCNQ2 and EEF1A2, RORA, GABAAR, VARIA-ATP1A3, SPATA5, DLG64, YWHAG, FZR1, KCNB1, KCNT1, SLC12A5, DNM1L, SCN2A.

To publish a call, please contact [Sébile Tchaicha](#), EpiCARE Research project manager.

[Calls for collaborative genetic research](#)

EVENTS



The 9th Annual Congress of the EANeurology is starting this week!

Find out more about the EAN2023 overarching theme "Neurology beyond the Big Data" and [register here](#).

EpiCARE will have a booth at the event, and we are looking forward to seeing you all in Budapest!

Save the date for the next Rome workshop!



4th Rome workshop on

Epilepsy care challenges from neonates to adults



December 13th to 15th, Rome, Italy

It is our pleasure to invite you to save the date of 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", a contribution to the activities of the ERN EpiCARE to translate into actions in Europe the WHO Directive on "Epilepsy and other neurological disorders".

The workshop will discuss in detail two important areas of epilepsy care:
Neonatal seizures and epilepsies
Epileptic Seizures in brain disorders

[Website is available here](#), and the registration will open soon!



- 17-28 July : San Servolo Epilepsy Course "Early pediatric onset epilepsies: from syndrome and management to future perspectives". [More info](#)
- 24-26 August: 13th ILAE School for Neuropathology and Epilepsy Surgery.
- 2-6 Sept : 35th International Epilepsy Congress in Dublin, Ireland. [More info](#).

EpiCARE SCIENTIFIC PUBLICATIONS

- Cossu, A., Lo Barco, T., Proietti, J., Dalla Bernardina, B., Cantalupo, G., Ghobert, L., Brambilla, I., Giarola, E., Costa, A., De Benito, T., Bethge, S., Cardot, S., Montwill, I., Remonato, E., Gramaglia, S., & Darra, F. (2023). Clinical characteristics of 80 subjects with KCNQ2-related encephalopathy: Results from a family-driven survey. *Epilepsy & behavior* : E&B, 142, 109153. [Link](#)
- Lo Barco, T., Corona, L., Solazzi, R., Fiorini, E., Galati, G., Cossu, A., Proietti, J., Francione, S., Dalla Bernardina, B., Darra, F., & Cantalupo, G. (2023). Gelastic seizures and "smiling spasms": A peculiar ictal pattern. *Epileptic disorders : international epilepsy journal with videotape*, 25(2), 269-273. [Link](#)
- Terman, S. W., Slinger, G., Rheau, C. E., Haque, A. S., Smith, S. N., van Griethuysen, R., van Asch, C. J. J., Otte, W. M., Burke, J. F., & Braun, K. P. J. (2023). Antiseizure Medication Withdrawal Practice Patterns: A Survey Among Members of the American Academy of Neurology and EpiCARE. *Neurology. Clinical practice*, 13(1), e200109. [Link](#)
- Cardenal-Muñoz, E., Auvin, S., Villanueva, V., Cross, J. H., Zuberi, S. M., Lagae, L., & Aibar, J. Á. (2022). Guidance on Dravet syndrome from infant to adult care: Road map for treatment planning in Europe. *Epilepsia open*, 7(1), 11-26. [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

July awareness days



AWARENESS DAYS



Upcoming

10th of July
GLUT1 Deficiency
Syndrome



ePAG EpiCARE newsletter

ePAG EpiCARE is establishing a Newsletter dedicated to patients' associations dedicated to rare and complex epilepsies.

If you are a patients' association and wish to disseminate the information about your association, projects, activities and events you are planning, please contact:

epag.epicare@gmail.com

If you wish to receive news from ePAG EpiCARE, [subscribe 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

a.robert@epi-care.eu

Follow us on social media!



EpiCARE



[Our mailing address is:](#)

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