



EpiCARE

EpiCARE MARCH 2022 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

Learn more every 2nd and 4th Thursday of the month with EpiCARE!



Hypothalamic hamartoma: electro-clinical picture and treatment options

April 14th at 17:00 CET

Mathilde Chipaux
&
Georg Dorfmuller

Register now

On the webinar webpage, you can check out the agenda for the next webinars and subscribe to the **webinars mailing** to get a reminder a few days before each webinar.

[Webinars webpage](#)

LATEST NEWS

ERN support Ukraine



The European Reference Networks are mobilised to help the rare disease community in Ukraine. Here are the actions taken so far:

- Common ERN website with **contact information** to reach each ERN:
<https://www.erncare4ua.com/>
- Dedicated **e-mail** address: ukraine.epilepsies@epi-care.eu
- Each medical team will ensure to patients coming from Ukraine a **fast access** to rare diseases specialists / referrals when needed
- EpiCARE medical teams and the ILAE are in contact with **pharmaceutical companies reg. medication shortage**
- Each medical team has the necessary **expertise to provide advice** on treatment
- When required, EpiCARE offers to HCPs a **conf. call with experts** to discuss diagnostic and treatment alternatives
- EpiCARE has contacts to help **translate essential medical documents** into nearly all EU languages
- The **Patient Advocates Group** and EURORDIS can provide information on nearby patient associations willing to provide **support** to families and patients from Ukraine

A word from our ePAGs

Growing a patient community!

We are happy to announce that the first introductory meeting was held with potential new members. Patient representatives come from many countries in Europe: France, Spain, Luxembourg, Netherlands, Norway, Italy and UK, and represent different organisations: European GRIN2B Association, Alternating Hemiplegia of Childhood UK, Une Etincelle Pour Isaure, Tess Research Foundation, SCN2A ITALIA – Famiglie in rete and L'Association d'Aide aux Personnes Epileptiques.

The associations represent patient community with different diseases: GRIN2B, Alternating Hemiplegia of Childhood (AHC), KCNT1, SLC13A5, SCN2A and a big epilepsy group which includes rare and complex epilepsies such as AHC and Panayiotopoulos syndrome.

We would like to welcome them to our community and we are looking forward to

continuing the activities with this wonderful, enthusiastic group!

EVENTS

Lots of interesting events coming up!



EPNS Glasgow 2022 Congress, 28 April - 2 May 2022 – hybrid meeting

The [EPNS Congress](#) provides an opportunity to learn about the latest developments in the rapidly evolving field of child neurology, including basic science, diagnostic methods, and novel treatments. You can network with colleagues and industry partners all focused on delivering the best possible care for children with neurological disorders.

Read the latest 'let's blether in Glasgow' [EPNS Congress newsletter](#)
Don't delay, [register today](#)

Email: katrin.volklund@intercongress.de

Solve-RD

**WORKSHOP:
NAVIGATING
THE SANDBOX**

Find out how to use the Solve-RD Sandbox, it's RD3 metadata layer & the Discovery-Nexus support capabilities

Thu, 19 May 2022
2 pm CEST

Joeri van der Velde University Medical Centre Groningen
Anthony Brookes University of Leicester
Colin Veal University of Leicester
Morris Swertz University Medical Centre Groningen

Solve-RD workshop: Navigating the Sandbox - 19th May 2022 - online

The Sandbox is the place where Solve-RD data & results are being stored, shared and further (jointly) analysed.

This combined webinar & workshop will provide an update on Solve-RD Sandbox services/functions, and also consider future plans, needs and possibilities. Intended participants include ERN data controllers/producers (to ensure that their data is being managed in ways they are happy with) and DITF members (to ensure they have services they need now and going forward).

[Register here](#)



Other events:

- 7-8 April: 5th Dianalund International Conference on Epilepsy. [More info](#)
- 10-13 April: EEG in the First Year of Life. [More info](#)
- 28 April - 2nd May: EPNS congress - see above. EpiCARE will have a booth, so come say hi!

EpiCARE SCIENTIFIC PUBLICATIONS

- Ley, M., Peláez, N., Principe, A., Langohr, K., Zucca, R., & Rocamora, R. (2022). **Validation of direct cortical stimulation in presurgical evaluation of epilepsy.** Clinical neurophysiology : official journal of the International Federation of Clinical Neurophysiology, 137, 38–45. Advance online publication. [Find the publication here.](#)
- Rocamora, R., Chavarría, B., Pérez, E., Pérez-Enríquez, C., Barguilla, A., Panadés-de Oliveira, L., Principe, A., & Zucca, R. (2021). **Mood Disturbances, Anxiety, and Impact on Quality of Life in Patients Admitted to Epilepsy Monitoring Units.** Frontiers in neurology, 12, 761239. [Find the publication in pdf here.](#) [in open-access](#)
- Sanchez-Larsen, A., Principe, A., Ley, M., Navarro-Cuartero, J., & Rocamora, R. (2021). **Characterization of the Insular Role in Cardiac Function through Intracranial Electrical Stimulation of the Human Insula.** Annals of neurology, 89(6), 1172–1180. [Find the publication here.](#)



You can consult recent publications on rare and complex epilepsies, epilepsy surgery and other topics on our [scientific publications webpage](#).

CASE DISCUSSIONS

EpiCARE Case Discussions are scheduled every 2nd, 3rd and 4th Wednesday of the month from 4:00pm to 5:30pm CET.

Both **surgical and non-surgical cases** are discussed by panels of experts, full or affiliated members of EpiCARE. [See the agenda on our website.](#)

To receive the link to join the case discussions, you must register. Registration is only required once to be placed on the mailing list. [Follow this link to register.](#)

Please note that Pr. Ingmar Blümcke is also organizing monthly online **neuropathology review** meeting of interesting and/or challenging epilepsy surgery cases.

This [Zoom link](#) will work for every meeting on **every second Thursday** per month in 2022.

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 !



[Our mailing address is:](#)

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[See in browser](#)