EpiCARE

NOVEMBER 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 WEBINARS

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

PATIENT'S COLLABORATION IN THE SEARCH FOR ANSWERS:
Research and data, multi-disciplinary care and growing a patient community.

December 8th at 17:00 CET

José Ángel Aibar
Dravet Syndrome Foundation Spain

Maryse Arendt
L'Association d'Aide aux Personnes Epileptiques AAPE Luxembourg

Vedrana Bibić,
Dravet syndrome Croatia

Register for this webinar

On the webinar wepage, 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 Coordinators meeting

Last week, all ERN Coordinators met in Lyon for their annual face-to-face meeting, as the EpiCARE Coordinator, Alexis Arzimanoglou, is chair of the ERN Coordinators group this year.

Various topics were discussed : the registry, their use of CPMS, involvment of the members of each ERNs... We also heard from all ERNs on their best initiatives, and it gave us a very positive outlook on the work in progress.

Visit of representants from HaDEA

Two weeks ago, we had the pleasure of welcoming 2 representants from the European Health and Digital Executive Agency (HaDEA), the agency of the European Commission in charge of the European Reference Networks.

Marilena Di Stasi and Theodor Haratau came to Lyon to learn more about our work, our governance and internal organisation, and meet our team in person. It was a great meeting, the perfect opportunity to share our goals and objectives and how we concretly work toward them.

EVENTS

Rome workshop : in search of lost time - 13-15 December, Rome, Italy

The third edition of the Rome workshop "In search of lost time" is taking place this winter, from December 13th to 15th !

REGISTER HERE - Watch out for the special rate for EpiCARE members!

Great news: The 3rd Rome workshop “From Epileptogenesis to Clinical Practice” will include a full 2 hours session on “Innovative findings from early career researchers”.
We selected 7 very talented researchers, and we are looking forward to meeting them in person and learn more about their research.

15th congress of the European Paediatric Neurology Society - 2023

Plans are now full steam ahead for the next EPNS Congress which will be taking place on 20-24 June 2023 in Prague, Czech Republic.
The programme is out! The main theme of the congress is “From genome and connectome to cure”. Take a look

Be the next winner! During the Congress three prizes will be awarded: Outstanding abstract, Best ePoster, Best Oral Presentation. The Awards will be presented during the congress. The three winners will receive a free registration for the 16th EPNS Congress in Munich, Germany. What you need to do for your chance to win? Submit your abstract by 31 December 2022.

Registration: opens in January 2023, so be sure to save the date in your diaries!

Keep informed: Sign up and get regular information. Scroll down to the end of the homepage. EPNS Congress 2023 video.
EPNS Membership: benefit from the substantially discounted member-only EPNS Congress registration fees and join the EPNS! 10 reasons to become an EPNS member. It is easy to join, just fill in our online application form.

If you have any questions whatsoever, please do not hesitate to contact info@epns.info or info@epns-congress.com.

Other upcoming events:

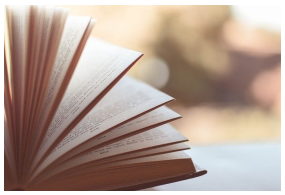
- 12 December: ePAG Exchange of Good Practice webinar - Experiences from patient-clinician teambuilding pilot sessions. More info
- 23 February - 25 June 2023: International Online Course on Pathogenesis of Epilepsy. More info
- 17-28 July : San Servolo Epilepsy Course "Early pediatric onset epilepsies: from syndrome and management to future perspectives". More info

EpiCARE SCIENTIFIC PUBLICATIONS

- Mitchell, J. W., Noble, A., Baker, G., Batchelor, R., Brigo, F., Christensen, J., French, J., Gil-Nagel, A., Guekht, A., Jette, N., Kälviäinen, R., Leach, J. P., Maguire, M., O'Brien, T., Rosenow, F., Ryvlin, P., Tittensor, P., Tripathi, M., Trinka, E., Wiebe, S., … Marson, T. (2022).
  Protocol for the development of an international Core Outcome Set for treatment trials in adults with epilepsy: the EPilepsy outcome Set for Effectiveness Trials Project (EPSET). Trials, 23(1), 943. Link.

- Brunklaus, A., Brünger, T., Feng, T., Fons, C., Lehikoinen, A., Panagiotakaki, E., Vintan, M. A., Symonds, J., Andrew, J., Arzimanoglou, A., Delima, S., Gallois, J., Hanrahan, D., Lesca, G., MacLeod, S., Marjanovic, D., McTague, A., Nuñez-Enamorado, N., Perez-Palma, E., Scott Perry, M., … Cestèle, S. (2022).
  The gain of function SCN1A disorder spectrum: novel epilepsy phenotypes and therapeutic implications. Brain : a journal of neurology, 145(11), 3816–3831. Link.

- Silvennoinen, K., Säisänen, L., Hyppönen, J., Rissanen, S. M., Karjalainen, P. A., D'Ambrosio, S., Jimenez-Jimenez, D., Zagaglia, S., Rothwell, J. C., Balestrini, S., Sisodiya, S. M., Julkunen, P., Mervaala, E., & Kälviäinen, R. (2022).
  Short- and long-interval intracortical inhibition in EPM1 is related to genotype. Epilepsia, 10.1111/epi.17466. Advance online publication. Link.

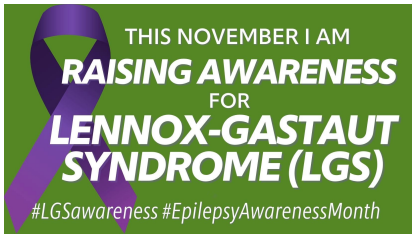


You can consult recent publications on rare and complex epilepsies, epilepsy surgery and other topics on our scientific publications webpage.

EpiCARE members: please remember to mention EpiCARE in your affiliations or in the acknowledgements / references when appropriate.

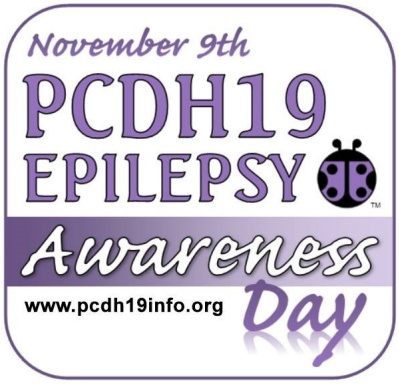
A word from our ePAGs

Lennox-Gastaut syndrome awareness day
November 1st was dedicated to Lennox-Gastaut syndrome!
Lennox-Gastaut syndrome (LGS) is a



rare epilepsy syndrome. No one is born with LGS, as it may develop over time. Children and adults with LGS share some similar electroclinical features, and comorbidities as well. It can have different background cause, and the progress of the disease is hard to prognose. Hence it is important to highlight LGS and raise awareness, as well as work actively on research and finding a better treatment options!

PCDH19 awareness day
9th of November we marked PCDH19 related epilepsy awareness day!
PCDH19 related epilepsy is a disease with a wide spectrum of severity in seizures, cognitive delays and other symptoms, which are all caused by a mutation of the PCDH19 gene on the X chromosome. Because of the gene location, girls are often affected, comparing to boys. Unfortunately, as in many other rare and complex epilepsies, there is a large diversity in seizure types, frequency and comorbidities including autism spectrum disorder.
All together they greatly influence the quality of life of each patient. In order to provide the best possible life for children, parents all over the word mark this day to spread the word and raise awareness!



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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