

Summer 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 to **forward** this newsletter... and here is the <u>link to sign up</u> and receive it regularly!

Summer Break!

The EpiCARE Coordination team will take its annual summer break in the month of August! There will be no educational webinars and no regular case discussions, with the exception, of course, of urgent cases. We are always reachable via e-mail, and all other activities are continuing. We are looking forward to September for a fresh start and an excellent European Epilepsy Congress, to be held in Rome, Italy!



Webinars

Thursday September 26th - 17h CET
Autoimmune Encephalitis and Immune-mediated Epilepsies

Presented by: Alberto Vogrig Chair: Masa Malenica

Register here

Our webinars take place once a month, and the replays are always available on our website. You can check the programme of the upcoming webinars and register to the mailing on the EpiCARE webpage:





Webinars webpage

Latest news

European Academy of Neurology

The EAN Congress was a resounding success, drawing a total of 7092 attendees onsite and 1932 virtual participants, from 123 different countries. This diverse and vibrant gathering showcased the global reach and impact of the event. For more highlights and memories, you can visit the EAN Gallery. We are excited to announce that the next edition of the EAN Congress will be held in Seville from June 21st to 24th, 2025. We look forward to seeing you there!



"Continuare a Curare"

The National Congress "Continuare a Curare" was a great success with more than 170 attendees! The event, endorsed by EpiCARE, various Italian scientific societies (LICE, SINPIA, SIN, SIP, etc.) and family organizations, aimed to address the needs of patients at the time of transition from childhood to adolescence and adulthood through a coordinated care model. It received significant attention and participation, highlighting the importance of addressing the challenges in transitioning care for patients with epilepsy and other neurological and/or psychiatric disorders and co-morbidities.



New Calls for Collaborative Genetic Research!

Please find the **new calls** published on the EpiCARE website to encourage participation in **collaborative genetic research projects**. The most recent ones are:

- Epilepsy spectrum in individuals with pathogenic KDM5C variants: a genotypephenotype characterisation (Rahel Burger: Berlin, Germany)
- Phenotype spectrum of patients with biallelic CACNA2D2 variants. (Gaetan Lesca: Lyon, France).
- Mapping clinical, EEG, and MRI signatures in STX1B epilepsies. (Stefan Wolking: Germany, Rikke S Møller: Denmark, Niels Focke: Germany).

Find out more about the collaborative research calls, <u>on this webpage</u>. If you have any question, feel free to contact <u>Sébile Tchaicha</u>, EpiCARE Research projects manager.

SAVE THE DATE!

December 16th - 18th 2024 (Rome, Italy) - "In search of lost time 5"

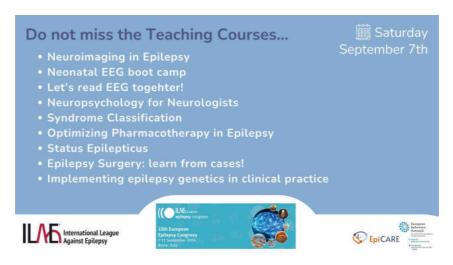


Upcoming events

SEPTEMBER

7th - 11th: 15th European Epilepsy Congress. Rome, Italy

The European Epilepsy Congress (EEC), organised by the **International League Against Epilepsy** (ILAE), is approaching! It will take place in Rome from 7 to 11 September. **Do not miss to <u>register</u>!**



You will find EpiCARE at booth number 423, along with the other **4 Neurological ERNs: ITHACA, ERN-RND, MetabERN** and **EURO-NMD**. Here you have more information about the congress and **the programme!**

17th - 20th: 16th International Epilepsy Course and Colloquium Frankfurt, Germany

The <u>16th International Epilepsy Colloquium and Course</u> will be held in **Frankfurt**, Germany. Experts from all over the world in the field of epilepsy surgery meet here every year with the aim of exchanging experiences and the latest findings and learning from each other in order to further improve the diagnosis and treatment of epilepsy.

25th - 26th: Epilepsy Pipeline Conference. Atlanta

The <u>Epilepsy Foundation Pipeline Conference</u> is held every two years to bring together decision-makers in the field of epilepsy treatment, therapeutic innovation, and product development. **The European Consortium for Epilepsy Trials (ECET)** will be represented.

A pre-congress, <u>round-table event</u>, organized by Julius Clinical, with contributions from the Directors of the Epilepsy Study Consortium and of ECET, is also planned.

OCTOBER

- 17th 19th: <u>Different faces of rare and complex epilepsies</u>
 <u>Conference</u>, Split (Croacia)
- 17th 18th: EPNS Research Meeting, Ljubljana (Slovenia)

EpiCARE Scientific Publications

- Vignatelli L, Tontini V, Meletti S, Camerlingo M, Mazzoni S, Giovannini G, Pasini E, Michelucci R, Bisulli F, Tinuper P, Di Vito L. Clinical practice guidelines on the management of status epilepticus in adults: A systematic review.
 Epilepsia. 2024;65(6):1512-1530. doi: 10.1111/epi.17982. Find the publication.
- Straka B, Splitkova B, Vlckova M, Tesner P, Rezacova H, Krskova L, Koblizek M, Kyncl M, Maulisova A, Bukacova K, Uhrova-Meszarosova A, Musilova A, Kudr M, Ebel M, Belohlavkova A, Jahodova A, Liby P, Tichy M, Jezdik P, Zamecnik J, Aronica E, Krsek P. Genetic testing in children enrolled in epilepsy surgery program. A real-life study. Eur J Paediatr Neurol. 2023;47:80-87. doi: 10.1016/j.ejpn.2023.09.009. Find the publication here.

- Sheikh IS, Katyal R, Hadjinicolaou A, Bibby BM, Olandoski M, Nascimento FA, Beniczky S. The online educational tool "Roadmap to EEGs" significantly improved trainee performance in recognizing EEG patterns. Epileptic Disord. 2024 Apr 30. doi: 10.1002/epd2.20227. Epub ahead of print. PMID: 38687239.
 Find the publication here.
- Nou-Fontanet L, Nguyen QTR, Bachoud-Levi AC, Reinhard C; Chorea & Huntington Disease Group ERN-RND; Ortigoza-Escobar JD. Insights from European Reference Network for rare neurological disorders study surveys on diagnosis, treatment, and management of NKX2-1-related disorders. Eur J Paediatr Neurol. 2024;51:110-117. doi: 10.1016/j.ejpn.2024.06.007. Find the publication here.



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

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

A word from our ePAGs

New Patient Journey: "GRIN Related Disorders"

We are excited to announce the new Patient Journey for GRIN Related Disorders! We would like to take this opportunity to thank **GRIN Europe** and **Dr. Antonela Riva** for their time, effort and collaboration invested in producing this document! Patient Journey is available 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

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