



EpiCARE

September 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 [link to sign up](#) and receive it regularly!

Next Webinar

Semiology of seizures in autoimmune encephalitides

10 October - 17:00 CET



Presented by:
Tobias Baumgartner and Andrea Stabile
Chaired by:
Maša Malenica



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

[Webinars webpage](#)

[Register here](#)

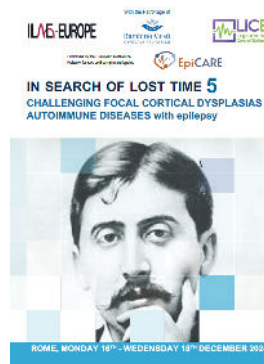
Latest news

REGISTER NOW!

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

We are delighted to announce that **Rome**, the eternal city, will once again welcome us for the 5th edition of the Workshop "In Search of Lost Time".

The nearly final **program** is now available and **registrations are open** (number of places limited).



We were in Rome for the EEC!

The European Epilepsy Congress in Rome was a great success, with nearly 3.600 attendees, over 130 sessions, and more than 400 speakers, chairs, and oral presenters. **Alexis Arzimanoglou**, ERN EpiCARE Coordinator, attended the congress together with **members of the EpiCARE Management team**, including Sébile Tchaicha, Belén Trebino, Johanna Van Hulle, and Laura Roig. Alexis Arzimanoglou, together with other EpiCARE members such as Nicola Specchio, Isabella Brambilla, Lieven Lagae, Helen Cross, Rima Nabbout, Stephane Auvin, Morten I. Lossius, Ronit Pressler, Philippe Ryvlin, and many other EpiCARE members, led interesting sessions that attracted much participation and generated innovative ideas. Thanks to the **ILAE** and to the organizing congress team, we were offered the opportunity to present the activities of EpiCARE and **4 other Neurological ERNs** at a booth. A big thank you to everyone who stopped by to meet us, have a chat, and learn more about the work being done by the Neurological ERNs, in line with the WHO action plan on “Epilepsy and Other Neurological Disorders”.



New Tool to Support EpiCARE Members with Clinical Trial Submissions in the CTIS

The **Working Group on Clinical Trials & Targeted Therapies**, coordinated by Floor Jansen, Rainer Surges and Valentina De Giorgis, has developed a new tool to assist ERN EpiCARE members **in submitting clinical trials through the Clinical Trial Information System (CTIS)**, the single point of entry for all clinical trials conducted within the European Union. We recognize that many investigators across the EU often face **the challenge of submitting their trials to regulatory authorities on their own**. To better support you, we have created these **guidelines** to streamline the process and provide clear, practical assistance.

**CTR CTIS
Guideline**

**ERN EpiCARE
DTA Template**

European Partnership Opens a New Era in Rare Disease Research

The European Rare Diseases Research Alliance (ERDERA) kicks off this September, with an estimated budget of 380 million euros and the aim of improving the lives of 30 million rare disease patients in Europe and beyond.

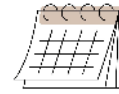
- The new partnership, championed by the European Union under [Horizon Europe](#) and Members States, is led by the National Institute of Health and Medical Research - [INSERM](#) (France). It integrates over 170 organisations from the public and private sectors to advance prevention, diagnosis and treatment research in rare diseases.
- The European Union is expected to contribute around 150 million euros to this co-funded partnership via Horizon Europe, while the rest of the funding will come from members states, countries associated to Horizon Europe and in cash and in-kind contributions from public and private partners.
- The alliance takes over the co-fund [EJPRD](#) to bring under one roof all knowledge, resources and services, boost clinical research and spur innovation to make Europe a world leader in this field.

- ERDERA will hold a launch event on 28 October 2024 to present its roadmap for the next decade.

Innov4-ePiK

We would like to introduce you to **Innov4-ePiK**, an [innovative project](#) dedicated to advancing research in developmental and epileptic encephalopathies, coordinated by Prof. **Rima Nabbout** at the **Institute Imagine** of Paris. The goal of this program is to develop **new diagnostic and therapeutic approaches for epileptic and developmental encephalopathies** related to potassium channel genes, using the 4Ps: personalised, predictive, preventive and participatory medicine. Heartfelt congratulations and gratitude to initiatives like this, which make significant progress in the field of epilepsy research.

Upcoming events



October



<p>✳️ 26èmes Journées Françaises de l'Epilepsie</p> <p>📍 <i>Marseille, France</i></p> <p>📅 8 - 11 October</p> 	<p>✳️ EPNS Research Meeting</p> <p>📍 <i>Ljubljana, Slovenia</i></p> <p>📅 17 - 18 October</p> 	<p>✳️ Different faces of rare and complex epilepsies Conference</p> <p>📍 <i>Split, Croatia</i></p> <p>📅 17 - 19 October</p> 	<p>✳️ The World Orphan Drug Congress Europe</p> <p>📍 <i>Barcelona, Spain</i></p> <p>📅 22 - 25 October</p> 
---	--	--	---

26èmes Journées Françaises de l'Epilepsie

[The Journées Françaises de l'Epilepsie](#) are coming to Marseille for the third time. The program includes Epileptology Teaching Days, sessions dedicated to paramedics, and scientific sessions on a variety of topics. We are sharing the [registration page](#) with you.

EPNS Research Meeting

Since 2008, the EPNS has been organizing [Research Meetings](#) aimed at advancing research in Pediatric Neurology. The meeting brings together leaders in the field, active researchers, and young fellows interested in joining or initiating research projects. [Registration](#) for this 2024 edition is now open.

Different faces of rare and complex epilepsies Conference

The second edition of [Different faces of rare and complex epilepsies Conference](#) will be held in Split, Croatia. The conference aims to foster knowledge sharing and productive discussions on rare and complex epilepsies. On the 18th, panel discussions for healthcare professionals will be conducted in English, and on the 19th, the panel discussions will be held in Croatian.

The World Orphan Drug Congress Europe

The [World Orphan Drug Congress](#) is the largest and most established orphan drugs & rare diseases meeting of its kind across the globe. Join over 2,000 attendees, listen to 250 leading speakers, and connect with 130 exhibitors as we bring together experts across the entire spectrum of orphan drug development.

EpiCARE Scientific Publications



- De Giorgis A, Pasca L, Aznar-Lain G, Bibic I, Bibic V, Darra F, Dianin A, Dressler A, Jonsson H, Komulainen-Ebrahim J, Kverneland M, Molteberg E, Ragona F, Saint-Martin A, Varesio C, Cross H. **Unraveling unmet needs in ketogenic dietary services: An ERN EpiCARE survey.** Doi: 10.1002/epi4.12968. [Open Access.](#)
- Barba C, Pelliccia V, Grisotto L, De Palma L, Nobile G, Gozzo F, Revay M, Carfi-Pavia G, Cossu M, Giordano F, Consales A, De Benedictis A, Cavallini E, Mion C, Accolla C, Specchio N, Nobili L, Guerrini R, Tassi L. **Trends, outcomes, and complications of surgery for lesional epilepsy in infants and toddlers: A multicenter study.** Doi: 10.1002/epi4.12965. [Open Access.](#)
- Rizzi M, Consales A, Tramacere I, De Benedictis A, Bua A, Specchio N, De Palma L, Cognolato E, Nobili L, Tortora D, Barba C, Pommella M, Giordano F, Pastori C, Marchetti M, Garbelli R, Zucchelli M, Martinoni M, Ferri L, Martucci M, Tamburrini G, Bianchi F, Passamonti C, Di Gennaro G, Villani F, Tassi L, Marras C. **Surgical and radiosurgical treatment of hypothalamic hamartoma: The Italian experience between 2011 and 2021.** Doi: 10.1002/epi4.12989. [Open Access.](#)
- Moya V, Adham A, Convers P, Lesca G, Mauguier F, Soulier H, Arzimanoglou A, Bayat A, Braakman H, Camdessanche J, Casenave P, Chaix Y, Chochoi M, Depienne C, Desportes V, De Ridder J, Dinkelacker V, Gardella E, Kluger G, Jung J, Lemesle M, Margherita M, Mueller M, Poulat A, Platzer K, Roubertie A, Stokman M, Vulto-van A, Wiegand G, Mazzola L. **Electro-Clinical Features and Functional Connectivity Analysis in SYN1-Related Epilepsy.** DOI: 10.1002/ana.27063. [Open Access.](#)

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.

Other ERNs in the field of Neurological Disorders

ERN ReCONNET will host its 2nd International Congress from April 9th to 11th, 2025, in Prague!

The Congress Committee and the **ERN ReCONNET** are pleased to invite you to the **2nd ERN ReCONNET International Congress on rare and low-prevalence connective tissue diseases**, which will take place in Prague, Czech Republic, on April 9th -11th, 2025.

Knowledge, awareness and a patient-centered approach have been the cornerstones of the activity of **ERN ReCONNET** in its first five years of activity, and the program reflects its mission and covers important topics in the diagnosis and management of rare and complex diseases (e.g., epidemiology, diagnosis and clinical management, biobanking, and registries).

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-

Follow us on social media!



You are receiving this e-mail because you subscribe to the EpiCARE newsletter.

[Unsubscribe](#)

© 2024 EpiCARE All rights reserved.

You are receiving this email as you may work at one of the EpiCARE centres or you are taking part in one or more of EpiCARE expert groups or you may have attended one of our webinars.

© 2024 Hospital Sant Joan de Déu (ERN EpiCARE)