



EpiCARE

The European Reference Network for
Rare and Complex Epilepsies

Newsletter

January 2026

Stay up to date on our upcoming events, educational and research activities, calls, and news from the coordination team, clinicians, researchers, nurses and Patient Advocate community. Feel free to **forward** this newsletter, and sign up [here](#) to receive it regularly!

Next webinar


Hemimegalencephaly: From Diagnosis to Surgical Treatment – A Multidisciplinary Approach

Date: **5 February 2026** / 17pm - 18:30pm

Speakers: **Katarzyna Kotulska /
Wiesława Grajkowska / Mikołaj Pielas /
Paweł Kowalczyk**

[Register here](#)



 You can now request a **certificate of attendance** after registering for and attending the webinars! Please email the [EpiCARE Helpdesk](#) afterward, and we'll send it to you.

Latest news

ERN EpiCARE's latest Open Access publication: a position paper identifying key priority areas for epilepsy research

This collaborative work brings together experts from multiple epilepsy-related disciplines across Europe, alongside patient advocates, highlighting the added value of European Reference Networks in fostering cross-border collaboration, advancing knowledge, and strengthening excellence in clinical care and research.

The paper has been shaped by the contributions of **EpiCARE's Working Groups** and, for the first time, also includes an appendix listing all healthcare providers hosting an EpiCARE medical team. We hope this publication will inspire new ideas, partnerships, and innovative collaborative projects in epilepsy research and care.

[Read it now!](#)

Received: 22 July 2023 | Revised: 5 December 2023 | Accepted: 14 December 2023
DOI: 10.1002/epi.15230

ORIGINAL ARTICLE

Epilepsia Open®

Areas of research priorities in epilepsy: A position paper of the European Reference Network for Rare and Complex Epilepsies, EpiCARE

Sébile Tchaicha^{1,2} | Stéphane Auvin^{2,3,4,5,6} | Sándor Beniczky^{7,8} | Andreas Brunklaus⁹ | Lieven Lagae^{2,10} | Emilio Perucca^{2,11,12} | Rainer Surges^{2,13} | Sophie Adler¹⁴ | Christoph Helmstaedter¹⁵ | Floor Jansen^{2,16} | Guido Rubboli^{2,14,17} | Philippe Ryvlin^{2,18} | Nicola Specchio^{2,19,20} | Eugen Trinka^{2,21,22,23} | Ingmar Blümcke²⁴ | Valentina de Giorgis^{2,25,26} | Katarzyna Kotulska^{2,27} | Gaetan Lesca^{2,28} | Masa Malenica^{2,29} | Amy McTague^{2,14,30} | Rima Nabhou^{2,31,32} | Rikke Steensbjerre Møller^{2,14,33} | Sandra Silva Arrieta^{34,35} | Isabella Brambilla^{36,36} | Malgorzata Kosla^{35,37} | Kees Braun^{2,15} | J. Helen Cross^{2,14,38} | Alexis Arzimanoglou^{2,2,39,40}

Correspondence: Alexis Arzimanoglou, EBN EpiCARE; Coordinator, Hospital Sant Joan de Déu, I.I.C. Centre d'Estudi d'Epilèpsia, DRUGS, Barcelona, Spain. Email: aarziman@jussorange.it

Abstract
Objective: To define and articulate research priorities in epilepsy identified by the European Reference Network for Rare and Complex Epilepsies (ERN EpiCARE), addressing key unmet needs across the spectrum of rare and complex epilepsies.
Methods: This position paper was developed through a structured collaborative process involving patient associations and experts from EpiCARE Working Groups, the EpiCARE Executive Committee, and its Research Council. Contributions were integrated and harmonized to establish a shared set of research priorities reflecting clinical, translational, and methodological perspectives.
Results: Six priority areas were identified and examined: prevention of epileptogenesis and disease-modifying challenges; genetics and targeted therapies; improved surgical decision-making; innovative trial designs and outcome measures; artificial intelligence for diagnosis and prediction;

Professors Kees Braun and J. Helen Cross are Chairs of the ERN EpiCARE; Research Council.
Professor Alexis Arzimanoglou is the Coordinator of the ERN EpiCARE.
For all authors refer to page 20.
This is an open access article under the terms of the [Creative Commons Attribution NonCommercial-NoDerivatives License](#), which permits use and distribution in any medium, provided the original work is properly cited, the use is non-commercial and no modifications or adaptations are made.
© 2024 The Author(s). *Epilepsia Open* published by Wiley Periodicals LLC on behalf of International League Against Epilepsy
[Epilepsia Open](#), 2024, 001–11. [wileyonlinelibrary.com/journal/epi](#) | 1

Understanding and treating DEE in infants with TSC

[The 5th Rome Debate on Developmental and Epileptic Encephalopathies](#) focuses on a critical and rapidly evolving challenge in pediatric neurology: **understanding and treating developmental and epileptic encephalopathies (DEE) in infants with Tuberous Sclerosis Complex (TSC)**. Early identification of pathogenic mechanisms and timely intervention are essential to altering the trajectory of the disease. This meeting aims to synthesize cutting-edge insights into the physiopathology of TSC-related DEE, as well as emerging strategies to prevent or modify epileptogenesis. Additionally, it fosters a platform for debate, knowledge exchange, and envisioning future directions in early diagnosis and intervention. Participation is **free of charge**, but registration is compulsory. [Please register via the event website!](#)

Upcoming events 2026

EPIPED 2026: Treatment Strategies in Paediatric Epilepsies
April 22 - 25th / Girona (Spain)

This course marks the third year of the 2024–2026 [EPIPED](#) cycle, a unique international training program designed to bridge geographical and knowledge gaps in epilepsy care.

Tailored for **child neurologists, physicians, and epilepsy nurses**, this 3-year program provides essential insights to enhance patient care and refine treatment practices. [The EPIPED program is now live!](#)



International Conference on TSC and Other Neurocutaneous Conditions
May 21 - 23th / Warsaw (Poland)

Registration is now open for *the International Conference on TSC and Other Neurocutaneous Conditions*. Neurocutaneous conditions belong to rare conditions, most of the genetic origin, frequently with drug-resistant epilepsy. During the Conference a high-class of international speakers will present **the current knowledge on diagnosis and**

their own reports as e-posters. There is also a possibility to include your own reports as e-posters.

Know EpiCARE Working groups!

Working Group 2: Clinical Genetics & Orphacodes

The identification of aetiological groups throughout the EU will provide appropriate genetic, metabolic and immune testing to a wider population.

[WG 2 webpage](#)



ERN EpiCARE Supporting Next Generation Epilepsy Experts

An important mission of EpiCARE is to support the education and training of young doctors and researchers already working in the field of rare and complex epilepsies. One concrete action toward this aim is [to support EpiCARE members in presenting their work at major scientific congresses in Europe](#). **Congresses available for 2026:**

12th Congress of the European Academy of Neurology

Geneva, Switzerland
27 - 30 June



16th European Epilepsy Congress

Athens, Greece
5 - 9 September



In Search of Lost Time 7 Workshop

Rome, Italy
11 - 13
November



EpiCARE Scientific Publications

Refining Aicardi Syndrome diagnostic Criteria: an expert-based consensus using a modified Delphi approach



Original article
Refining Aicardi Syndrome diagnostic Criteria: an expert-based consensus using a modified Delphi approach

Silvia Masnada^{1*}, Valentina De Giorgis^{2,3,4}, Umberto Carugo^{5,6}, Nadia Bahi-Buisson^{7,8}, Mara Cavallini⁹, Marie Garbett¹⁰, Mambola Formica¹¹, Jozsef Gecz¹², Natalia Petros¹³, Emilio Perucca¹⁴, Anna Pichiecchio^{15,16}, Paolo Fusar-Poli^{17,18}, Elliott H. Sherr¹⁹, Ignatia B. Van den Veyver²⁰, Federico Zara²¹, Martin Geroldinger²², Pierangelo Veggioni²³, Alexis Arzimanoglou^{24,25}, on behalf of the Aicardi Syndrome Study Group

1. Hôpital Necker – Enfants Malades, Paris, France; 2. Hôpital de la Pitié-Salpêtrière, Paris, France; 3. Hôpital de la Sainte-Justine, Paris, France; 4. Hôpital de la Pitié-Salpêtrière, Paris, France; 5. Hôpital de la Pitié-Salpêtrière, Paris, France; 6. Hôpital de la Pitié-Salpêtrière, Paris, France; 7. Hôpital de la Pitié-Salpêtrière, Paris, France; 8. Hôpital de la Pitié-Salpêtrière, Paris, France; 9. Hôpital de la Pitié-Salpêtrière, Paris, France; 10. Hôpital de la Pitié-Salpêtrière, Paris, France; 11. Hôpital de la Pitié-Salpêtrière, Paris, France; 12. Hôpital de la Pitié-Salpêtrière, Paris, France; 13. Hôpital de la Pitié-Salpêtrière, Paris, France; 14. Hôpital de la Pitié-Salpêtrière, Paris, France; 15. Hôpital de la Pitié-Salpêtrière, Paris, France; 16. Hôpital de la Pitié-Salpêtrière, Paris, France; 17. Hôpital de la Pitié-Salpêtrière, Paris, France; 18. Hôpital de la Pitié-Salpêtrière, Paris, France; 19. Hôpital de la Pitié-Salpêtrière, Paris, France; 20. Hôpital de la Pitié-Salpêtrière, Paris, France; 21. Hôpital de la Pitié-Salpêtrière, Paris, France; 22. Hôpital de la Pitié-Salpêtrière, Paris, France; 23. Hôpital de la Pitié-Salpêtrière, Paris, France; 24. Hôpital de la Pitié-Salpêtrière, Paris, France; 25. Hôpital de la Pitié-Salpêtrière, Paris, France

Authors: Silvia Masnada, Valentina De Giorgis, Umberto Carugo, Nadia Bahi-Buisson, Mara cavallini, Mark Corbett, Manuela Formica, Jozsef Gecz, Natalia Petros, Emilio Perucca, Anna Pichiecchio, Paolo Fusar-Poli, Elliott H. Sherr, Ignatia B. Van den Veyver, Federico Zara, Martin Geroldinger, Veggioni Pierangelo, Alexis Arzimanoglou, on behalf of the Aicardi Syndrome Study Group.

[Read it now!](#)

Long-term outcomes of epilepsy surgery: A 25-year experience from a tertiary referral center



Authors: Almeida M, Barros F, Cunha Ines, Brás A, Teotónio R, Bento C, Sales F

[Read it now!](#)

You can consult recent publications related to the diagnosis and treatment of rare and complex epilepsies on our [scientific publications webpage](#).

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 l.roig@epi-care.eu

Follow us on social media!



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

[Unsubscribe](#)

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.

© 2026 Hospital Sant Joan de Déu (ERN EpiCARE)