



EpiCARE

The European Reference Network for
Rare and Complex Epilepsies

Newsletter

June 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!

Latest news

EpiCARE Annual Meeting 2026 (Leuven, Belgium)



15

Sessions

~130

On-site participants

26

Countries

In-person meetings are where the network's real work gets done — relationships, trust, and the informal exchange that no platform replicates.

The **EpiCARE Annual Meeting 2026** took place from 15 to 19 June in Leuven, bringing together members from **across Europe** for several days of collaboration and knowledge exchange. The programme spanned Management Team, Executive Committee, and Working Group sessions, alongside the General Assembly, with presentations, strategic discussions, and updates on the network's priorities. Participants also attended scientific lectures covering recent advances in the field.

The meeting reflected EpiCARE's commitment to **education, innovation, and multidisciplinary collaboration** — and, most importantly, reinforced the value of working together to improve the **diagnosis, treatment, and care of epilepsy patients across Europe**.

We would like to thank all participants for their engagement, contributions, and continued dedication to the EpiCARE network.

Sharing with you an updated version of the [booklet](#) summarizing all EpiCARE Working Group activities and a selection of [EpiCARE-enabled publications](#) born from cross-boarders collaborations.

Collaborative Clinical Research calls

Through this **Collaborative Clinical Research** section, we share opportunities for collaborative clinical research initiatives, such as natural history studies. The main aim of this initiative, supported by the EpiCARE network, is to facilitate the recruitment of patient cohorts across epilepsy centres.

Recent calls:

- [Spike-Wake activation during sleep in Phelan-McDermic syndrome](#), coordinated by Ludovica Pasca & Valentina De Giorgis.
- [Metabolism in Tuberosous Sclerosis Complex](#), coordinated by Floor Jansen and Daoud Abu Husein

Survey on Barriers in epilepsy research for early-career researchers

We would like to invite you to participate in a short survey exploring the main barriers and potential solutions to conducting epilepsy research in Europe.

This survey is intended for **early-career researchers**, defined as professionals with **less than 10 years of experience in epilepsy research**, including PhD students, postdoctoral researchers, clinician-researchers, allied healthcare professionals, and other professionals involved in epilepsy research.

Your feedback will help identify current challenges and inform future initiatives to better support the next generation of epilepsy researchers across Europe.



Estimated time: 7 minutes



Deadline to respond: 17 July 2026



[Survey link](#)

We greatly appreciate your time and contribution.



Upcoming events 2026 - 2027

16th European Epilepsy Congress (EEC) 2026

[September 5 - 9, 2026 / Athens \(Greece\)](#)

The [16th European Epilepsy Congress](#), organised by the International League Against Epilepsy (ILAE), will bring together clinicians, researchers and healthcare professionals from across the globe to share the latest advances in epilepsy research, diagnosis and treatment. The scientific programme will feature keynote lectures, symposia, educational courses, abstract presentations and valuable networking opportunities, fostering collaboration and innovation within the epilepsy community.



Know EpiCARE Working groups!

Working Group 6: **Neuropathology**

Microscopic tissue diagnosis of human brain disorders remains the gold standard in modern medicine. Yet, histopathology training in epileptic disorders is difficult to obtain in many European countries

WG 6 webpage

Working Group 7: **Targeted Medical Therapies**

For many of the rare and complex epilepsies, approved and evidencebased treatments do not exist. Thus, there is an urgent need to support high quality evidence of clinical studies and to identify and develop novel treatments targeting specific aetiologies.

WG 7 webpage



ERN EpiCARE Supporting Next Generation Epilepsy Experts

An important mission of EpiCARE is to **support the education and training of early-career experts** 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:

In Search of Lost Time Workshop 7

- [Deadline for abstract submissions: July 20th 2026](#)
- [Registrations are now open](#)



In Search of Lost Time 7 – Scientific Program (Preliminary) Rome, November 11th-13th 2026

We are delighted to welcome you to the 7th edition of In Search of Lost Time, a workshop designed to bring together the many disciplines involved in the care and research of complex epilepsies. Clinicians, researchers, geneticists, surgeons, neurophysiologists, patient advocates, and industry partners will share knowledge and perspectives on the rapidly evolving field of precision medicine: epilepsy surgery, drug-resistant focal disorders, and emerging therapies. Beyond scientific advances, it is meeting aims to foster open dialogue and collaboration, allowing to discuss what matters most for patients and families in improving quality of life and long-term outcomes. The scientific workshop goals to share and make this workshop and news articles, meetings, publications, not accessible for a participants.

Scientific Organizing Committee

Christine Morris-Spencer, Anna Aramengo

Silvia Striano, Maria
Suzanne, Anna
Carmen, Maria
Karin, Maria
Andrea, Maria
Claudia, Maria
Helen, Maria
Carmen, Maria
Pier, Maria

Diana, Maria
Gustavo, Maria
Luis, Maria
Gustavo, Maria
Anna, Maria
Andrea, Maria
Laura, Maria
Martin, Maria
Roberto, Maria

Correale, C., Specchio, N., Downs, J., Cross, J. H., Cappelletti, S., Palacio-Navarro, A., Geuens, S., Valente, K., Brunklaus, A., & Reilly, C. (2026). [Cognitive and behavioral clinical outcome assessments in children with developmental and epileptic encephalopathies: Issues and instruments](#). *Epilepsia*, 10.1002/epi.70308. Advance online publication.

Fortunato F, Selvatici R, Kirschner J, et al. [European Reference Networks as core health structures where referring genetic newborn screening positive infants: an innovative operational research framework](#). *Front Public Health*. 2026;14:1822461. Published 2026 Jun 10.

Auvin, S., Arzimanoglou, A., French, J., Knupp, K. G., Lagae, L., Trinka, E., Dlugos, D., & Perucca, E. (2026). [Evolution of the European Medicines Agency clinical guidelines for epilepsy drug development between 2010 and 2025: A comparative analysis by the ILAE Task Force on Regulatory Affairs](#). *Epilepsia*, 67(6), 2743–2754.

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!



[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)