



EpiCARE

The European Reference Network for
Rare and Complex Epilepsies

Newsletter

March 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


ASM, to treat or not to treat

Date: **30 April 2026** / 17pm - 18:30pm

Speaker: Pr. **Morten Lossius** (*Member of the EpiCARE Executive Committee - National Centre for Epilepsy, Oslo, Norway*)

[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

EpiCARE Annual Meeting 2026

Leuven (Belgium)
16 - 18th June 2026



Invitation to sign the Declaration on a European Innovation and Care Ecosystem for Rare and Complex Diseases

ERN EpiCARE invites members, partners, and patient advocates to sign the Declaration on a European Innovation and Care Ecosystem, launched in Brussels in Dec 2025. This multi-stakeholder initiative unites patients, clinicians, researchers, and industry to accelerate progress. It

outlines 8 Priority Actions to improve diagnostics, treatment access, clinical trials, real-world evidence, and secure funding for ERNs. Your endorsement can make a real difference for patients across Europe. [Click the link to sign and support the movement.](#)



[Read the full invitation](#)

A strong message from Mrs. Donata Meroni, DG SANTE Head of Unit for Health monitoring and cooperation

'Rare Diseases are not rare – nor are rare disease success stories!'

The EU's work on cross-border healthcare and the European Reference Networks is helping rare disease patients across Europe access accurate, timely diagnoses, as well as the care and treatment they need. **Donata Meroni** provides further insight into these developments in the [following interview](#), which we are pleased to share with you.



Dravet Syndrome Research Kit

The [DS Research Kit](#) is an open-access initiative led by the **Dravet Syndrome Foundation Spain** aimed at **accelerating basic and preclinical research in Dravet syndrome**. The kit provides a collection of validated molecular tools, including two well-characterized SCN1A mouse models and a human Nav1.1-GFP plasmid, currently used by numerous academic and biotechnology groups worldwide. These resources have supported more than twenty scientific publications and contributed to the development of several advanced therapeutic strategies.

DS Research Kit:
Tools for open-access investigation in Dravet syndrome



Overview
The DS Research Kit was initiated by the Dravet Syndrome Foundation Spain, dedicated to scientific, basic and clinical research in Dravet syndrome. The program provides open-access, scientifically validated and fully characterized tools for basic research, preclinical studies and the development of novel therapeutic strategies.
By promoting scientific rigor, transparency and access across the DS Research Kit, we foster international collaboration and stimulate new discoveries.

All components are openly accessible through international repositories to promote collaboration, reproducibility, and innovation in the field

Upcoming events 2026

Paros Meeting

May 11 - 15, 2026 / Paros (Greece)

The second edition of Paros meeting (endorsed by EpiCARE, International League Against Epilepsy and Epileptic Disorders) will focus on the theme of "Direct cortical stimulation during SEEG".

As the meeting is now sold out for in-person attendance, [a virtual participation option is available](#). Join 55 world-leading experts from 22 countries!

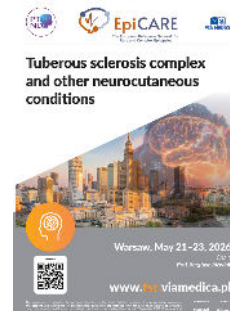


International Conference on TSC and Other Neurocutaneous Conditions May 21 - 23, 2026 / Warsaw (Poland)

Registration is still open for the [International Conference on TSC and Other Neurocutaneous Conditions!](#)

During the Conference a high-class of international speakers will present the current knowledge on diagnosis and therapeutic possibilities in these conditions.

[The program is now available.](#)



Low registration fee or fee waiver in case of first authorship for residents during the EPICARE-patronage conference in Warsaw. Create an account and register via the website. In case of problem please contact tsc@viamedica.pl or s.jozwiak@ipczd.pl.

12th Congress of the European Academy of Neurology June 27 - 30, 2026 / Geneva (Switzerland)

The European Academy of Neurology (EAN) Congress is one of the world's leading events in neurology. This annual hybrid meeting brings together clinicians, researchers, educators, industry partners, residents, students, and patient representatives for four days of cutting-edge science and professional development. [Register now!](#)



We would like to remind you that [eanCampus](#) offers monthly webinars, masterclasses and podcasts. Below are two webinars we would like to highlight:

- 31.03.2026, 3 - 4:30pm CET | **'Basic Statistics for Neurologists' (Neuroepidemiology)**, by Rosario Vasta, Yihan Hu, Ruben Van Eijk.
- April 2026 | **'AI in Neurology: Augmentation or Automation?'**, by Harris Sotirakis, Maria Chiara Malagutti.

Know EpiCARE Working groups!

Working Group 18: **Epilepsy beyond seizures**

Psychosocial issues, quality of life, sleep disorders, patient perspectives (PROMS), sexuality, ASM adherence and many others, are essential to a comprehensive care of the epilepsies, independently of age and seizure severity.

[WG 18 webpage](#)



"Proceedings from ERN EpiCARE "BEYOND SEIZURES" meeting, Aalesund, Norway, May the 27th. Advancing holistic care for rare and complex epilepsies in adults"

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.](#)

Next congresses available 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

- ['International Consensus on the Evaluation and Management of Hypothalamic Hamartomas'](#) - Cohen N, Li X, Berl M, Oluigbo C, Shirozu H, Berkovic S, Zacharin M, Maixner W, Schulze-Bonhage A, Klotz K, Specchio N, Ferrand-Sorbets S, Bulteau C, Arzimanoglou A, Regis J, Cross J, Tisdall M, Richardson H, Cukiert A, Cukiert C, Jacobs J, Donner E, Pearl P, Kerrigan J, Wilfong A, Yuen K, Dlugos D, Curry D, Ali I, Ragheb J, Soeby L, Webster E, Gaillard W (March 2026).
- ['Evaluating executive functions in children and adolescents with epilepsy using the EpiTRACK tool: A 5-year longitudinal follow-up study'](#) - Motos T, Abarca ML, Ramírez-Camacho A, Medina Rivera I, López-Sala A, Nou-Fontanet L, Valero Coppin O, Arzimanoglou A, Palacio-Navarro A (February 2026).
- ['Defining the end point of status epilepticus: A scoping review and framework for standardization'](#) - Khan F, Gopaul M, Carter S, Chimakurthy A, Skelton S, Hirsch L, Trinka E (February 2026).
- ['Clinical and genetic landscape of epilepsies with absence seizures and single-gene etiology'](#) - Balestrini S, Galli I, Ricci M, Parrini E, Mei D, Mastrangelo M, Pisani F, Filippi C, Giordano L, Cesaroni E, Marini C, Cerulli Irelli E, di Bonaventura C, Rubino M, Coppola A, Proietti J, Lo Barco T, Darra F, Licchetta L, Bisulli F, Perulli M, Battaglia D, De Dominicis A, Trivisano M, Specchio N, Solazzi R, Caputo D, Canafoglia L, Guerrini R (September 2025).

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

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

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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.

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