



# EpiCARE • Newsletter

The European Reference Network  
for Rare and Complex Epilepsies

September 2025

If you want to be informed about our next events, educational and research activities, calls, but also receive news from the coordination team, our clinicians, researchers, nurses and our Patient Advocate 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 webinars

*'How to manage ketogenic diet therapies for refractory status epilepticus'*

### Webinar

DATE  
16th October 2025

TIME  
17 - 18:30PM

PRESENTED BY  
Mackenzie Cervenka and  
Martin Kynčl



*'How to use AI in clinical EEG interpretation'*

### Webinar

DATE  
23th October 2025

TIME  
17 - 18:30PM

PRESENTED BY  
Sandor Beniczky



*"How to manage ketogenic diet therapies for refractory status epilepticus"*

Present by: **Mackenzie Cervenka and  
Natasha Schoeler**

[Register here](#)

*"How to use AI in clinical EEG interpretation"*

Present by: **Sandor Beniczky**

[Register here](#)

Our webinars take place **once a month**, and [the recordings are always available on our website](#).

## Latest news

**EpiCARE at the International Epilepsy Congress 2025 in Lisbon  
A Great Success!**



The [36th International Epilepsy Congress](#) in Lisbon exceeded all expectations, bringing together over **4.200 participants** worldwide.

Our EpiCARE team had an active presence at **Booth 410**, where we shared extensive information about our activities and welcomed **many visitors**. The booth, offered by the ILAE, also hosted many F2F meetings of our Working Groups. A welcoming place to meet colleagues and friends.

Special thanks to **Ronit Pressler, Nicola Specchio, Sébile Tchaicha, Rima Nabbout, Alexis Arzimanoglou**, and many others for their outstanding talks and insights.

A big thank you as well to everyone who visited us. Your engagement made the IEC 2025 truly memorable!

### Supporting Early-Career Epilepsy Experts



At the IEC 2025, we had the pleasure of welcoming the [early-experts supported by EpiCARE](#) to present their work. For this congress, the experts selected by EpiCARE were: **Lisa Evju** (Norway), **Anna Scarabello** (Italy), **Jinping Zhou** (Freiburg) and **Katrine Marie Johannesen** (Denmark).

[Watch their testimonials!](#)

### New opportunities for research projects in epilepsy surgery

The new webpage "[Collaborative research on Presurgical evaluation and Epilepsy Surgery](#)" is open and accepting proposals. You will find it within the new section "[EpiCARE Collaborative Research Calls](#)."



## EpiCARE Scientific Publications

Received: 11 October 2024 | Revised: 8 April 2025 | Accepted: 20 April 2025  
DOI: 10.1002/epi.47007

ORIGINAL ARTICLE Epilepsia Open®

### Genetic etiologies with a large NGS panel in a monocentric cohort of 1000 patients with pediatric onset epilepsies

Giulia Barcia<sup>1,2,3</sup> | Nicole Chemaly<sup>3,4</sup> | Stéphanie Gobin-Limballe<sup>3</sup> | Emma Losito<sup>3,4,5</sup> | Mélodie Aubart<sup>6</sup> | Eugénie Sarda<sup>4</sup> | Zahra Assouline<sup>1,2</sup> | Pauline Plante-Bordeneuve<sup>1,2</sup> | Marie Hully<sup>7</sup> | Remi Barrois<sup>3,4,5</sup> | Christine Barnerias<sup>4</sup> | Doxa Sareidaki<sup>3,4</sup> | Delphine Coste-Zeitoun<sup>3,5</sup> | Monika Eisermann<sup>3,5</sup> | Cécile Fourrage<sup>3</sup> | Sylvain Hanein<sup>2</sup> | Marlène Rio<sup>3</sup> | Nathalie Boddaert<sup>6</sup> | Isabelle Desguerre<sup>4</sup> | Anna Kaminska<sup>1,5</sup> | Julie Steffann<sup>1,2</sup> | Rima Nabhout<sup>2,3,4</sup>

**Abstract**  
**Objective:** Genetic testing is now included in the diagnostic assessment of childhood onset epilepsies. We evaluated the yield of a targeted next generation sequencing (NGS) panel dedicated to pediatric epilepsies.  
**Methods:** We tested by NGS panel 1000 consecutive patients presenting with childhood onset epilepsies and including mainly patients with early onset epilepsies (under 2 years, 61%).  
**Results:** Causal variants were identified in 31% of patients, spanning 76 different genes. Patients with benign familial neonatal/infantile epilepsy (BFNE/IFE) exhibited the highest rate of positive findings (82%). Developmental and epileptic encephalopathies (DEEs) had a global diagnostic yield of 37%, with epilepsy of infancy with migrating focal seizures (EIMFIS) and Dravet syndrome (DS) presenting the highest yield in this group (78%) and early infantile DEE

**Genetic etiologies with a large NGS panel in a monocentric cohort of 1000 patients with pediatric onset epilepsies**

Received: 12 March 2025 | Revised: 4 May 2025 | Accepted: 12 May 2025  
DOI: 10.1002/epi.47015

ORIGINAL ARTICLE Epilepsia Open®

### Is highly purified cannabidiol a treatment opportunity for drug-resistant epilepsy in subjects with typical Rett syndrome and CDKL5 deficiency disorder?

Aglaia Vignoli<sup>1,2</sup> | Giulia Prato<sup>3</sup> | Enrico Alfei<sup>4</sup> | Irene Bagnasco<sup>5</sup> | Alberto Danieli<sup>6</sup> | Massimiliano Celario<sup>7,8</sup> | Jacopo Favaro<sup>9,10</sup> | Sara Matricardi<sup>11</sup> | Francesca Felicia Operto<sup>12</sup> | Alessandro Orsini<sup>13</sup> | Davide Paolo Bernasconi<sup>14,15</sup> | Nicola Pietrafusa<sup>16</sup> | Emilia Ricci<sup>17,18</sup> | Luca Manfredini<sup>19</sup> | Giulia Ballette<sup>1</sup> | Paolo Bonanni<sup>2</sup> | Maria Paola Canevini<sup>23,27</sup> | Valentina De Giorgis<sup>24</sup> | Lino Nobili<sup>25</sup> | Stefano Sartori<sup>16,19</sup> | Miriam Nella Savini<sup>27</sup> | Ilaria Viganò<sup>17</sup> | Nicola Specchio<sup>16,19</sup>

**Abstract**  
**Objective:** This study aimed to evaluate the efficacy and safety of adjunctive, highly purified Cannabidiol (Epidiolex®) in individuals with drug-resistant epilepsy (DRE) due to genetically determined typical Rett Syndrome (RTT) and CDKL5 Deficiency Disorder (CDD).  
**Methods:** We recruited subjects with genetically confirmed typical RTT and CDD with drug-resistant seizures who received add-on treatment with highly purified Cannabidiol (CBD) through a national collaboration group. CBD treatment was titrated from 5 to 20 mg/kg/day; concurrent antiseizure medications (ASMs) could have been adjusted as clinically indicated.

**Is highly purified cannabidiol a treatment opportunity for drug-resistant epilepsy in subjects with typical Rett syndrome and CDKL5 deficiency disorder?**

## News from other ERNs

### Registration open for the ERN-RND Scientific Symposium

As part of the **ERN-RND Annual Meeting 2025**, a **Scientific Symposium** (Tuesday 28th October) will be **open to anyone interested** in joining remotely. This session will explore the status of European healthcare for rare neurological diseases within the ERNs, including discussions on cross-border access to highly specialised therapies, multidisciplinary case studies, and the integration of ERNs into national healthcare systems. **Alexis Arzimanoglou**, EpiCARE coordinator, will give the session "Epilepsy Surgery as an EpiCARE use case" at 10:40CET. [Register!](#)

ALEXIS ARZIMANOGLOU  
**Epilepsy Surgery**  
as an epiCARE use case

28<sup>th</sup> October 2025 | 10:40 CET



ERN-RND Scientific Symposium

## European Healthcare for RND Patients



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](mailto:l.roig@epi-care.eu)

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