



## June 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!

### 2024 EpiCARE Annual Meeting

EpiCARE organized its 7th Annual Meeting from June 17th to 19th in Barcelona. The event welcomed on site over **120 participants from 28 different countries across Europe** at the Abba Garden Hotel in Barcelona! Many other members participated remotely to the Working Group sessions.



The event began early Monday morning with the face-face to-face meeting of the **Executive Committee**. Monday afternoon was reserved for **parallel sessions of 16 working groups** to discuss future actions. **The General Assembly** was held throughout Tuesday 18th, and the debates in parallel workshops continued Wednesday morning.

We want to express our deepest gratitude to everyone for your commitment and passion for EpiCARE missions. Thank you for joining us and making this gathering a true success. Here you have [some pictures](#) of these days.

The 2025 annual meeting will be hosted by our EpiCARE members at the **SALK University**, in **Salzburg**, Austria. Looking forward to getting together again!

*Webinars*

## New Gene Therapy Webinar Series

The [webinar series on Gene Therapy](#) is co-organized by ERN-RND, EURO-NMD, ERN EpiCARE and the European Academy of Neurology (EAN). Together we'll delve into the latest advancements and breakthroughs in this interesting field!

- **02.07.2024**, 4 pm CEST | 'State of the Art of Clinical Stage Gene Therapies for Leukodystrophies' by Caroline Sevin, Kremlin Bicêtre Hospital, France. [Registration here](#).
- **23.07.2024**, 4 pm CEST | 'Genetic Therapies and Therapy Developments for Rare Movement Disorders (HD, SCA)' by Willeke van Roon-Mom, Leiden University Medical Center, the Netherlands. [Registration here](#).



## Latest news

### Save the date!

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



### MOOC: Are you looking to learn more about rare disease research?

We have co-developed several **Massive Open Online Courses (MOOCs)** with EJPRD to help expand your knowledge on topics such as genetic testing, health data usage, and translational and diagnostic research. Watch the trailer [here!](#)

You can still sign up:

[Join the course](#)



## JUNE

### **EAN (European Academy of Neurology). Helsinki, Finland. Date: 29 - 2**

The 10th **Congress of the European Academy of Neurology** is taking place in Helsinki and in an online format. The main theme of the congress is **'Neuromodulation: advances and opportunities in neurological diseases'** which will be the focus of several sessions. [The congress programme](#) will offer symposia, workshops, teaching sessions, and much more.



## JULY

### **"Continuare a curare". Pavia, Italy. Date: 4- 5**

"Continuare a curare" offers **Interdisciplinary working models to support the transition to adulthood in neurological and psychiatric disorders**, organized by SINPA (Italian Society of Neuropsychiatry Childhood and Adolescence) supported by the "Transition" special interest group of ERN EpiCARE. The [course](#) is designed for medical specialists in Neurology, Child Neuropsychiatry, Paediatrics, Neurophysiopathology, Paediatrics, General Medicine and Psychiatry.



## SEPTEMBER

### **15th European Epilepsy Congress. Rome, Italy. Date: 7-11**

European Epilepsy Congress (EEC), organised by the International **League Against Epilepsy (ILAE)**, will take place in Rome from 7 to 11 September. The EEC is a landmark in the epilepsy community agenda and the forthcoming EEC promises to be innovative and engaging. ERN EpiCARE organizes or contributes to many of the sessions. Here you will find [more information](#) about the congress and the programme!

### **2024 Epilepsy Pipeline Conference. Atlanta. Date: 25- 26**

[Epilepsy Foundation Pipeline Conference](#) is held every two years to bring together **decision-makers in the field of epilepsy treatment, therapeutic innovation, and product development**. This exciting meeting provides a forum for evaluating new therapies in development, exploring future advancements, and encouraging collaborations and partnerships. [A round table event](#) co-organized by Julius and European Consortium for Epilepsy Trials (ECET) is also planned.

- Papadopoulou MT, Muccioli L, Bisulli F, Klotz KA, Fons C, Trivisano M, Kabulashvili T, Specchio N, Lesca G, Arzimanoglou A. **Accessibility, availability and common practices regarding genetic testing for epilepsy across** **9(3):996-1006**. doi: 10.1002/epi4.12930. [Open Access](#).
- Amin S, Møller RS, Aledo-Serrano A, Arzimanoglou A, Bager P, Józwiak S, Kluger GJ, López-Cabeza S, Nabbout R, Partridge CA, Schubert-Bast S, Specchio N, Kälviäinen R. **Providing quality care for people with CDKL5 deficiency** **9(3):832-849**. doi: 10.1002/epi4.12914. [Open Access](#).
- Pressler RM, Abend NS, Auvin S, et al. **Treatment of seizures in the neonate: Guidelines and consensus-based recommendations-Special report from the ILAE Task Force on Neonatal Seizures**. *Epilepsia*. 2023;64(10):2550-2570. doi:10.1111/epi.17745. [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

### Summer schools tailored for professionals in the field of neuromuscular diseases!

Dear EURO-NMD community,

we are excited to announce not just one, but two summer schools:

- [Neuromuscular translational summer school](#) (6<sup>th</sup> edition)
  - **Dates:** 9 – 12 July 2024
  - **Location:** Leiden University Medical Center, The Netherlands
- [Summer school on Multidisciplinary Management of Neuromuscular Diseases](#) (1<sup>st</sup> edition)
  - **Dates:** 12 – 14 September 2024
  - **Location:** Marseille, France

Whether you are an experienced professional or you are just starting in the field, these programs promise to enrich your knowledge and advance your skills in the dynamic realm of neuromuscular medicine!



A word from our ePAGs

## First online meeting with patient organisation for rare and complex epilepsies in Europe

"Together for rare and complex epilepsies" meeting was organised after receiving positive feedback from patient organisations. The survey received 89 responses, and all the participants expressed their interest in joining the first online meeting with the patient community, held on May 31st 2024. During the meeting 55 participants joined online. The speakers were prof. Alexis Arzimanoglou, Isabella Brambilla, Vedrana Bibić, Malgorzata Kosla, Irena Bibić, Matt Bolz Johnson and Kathy Redmond. The topics discussed were:

- ERN EpiCARE and ePAG activities
- Patient Journeys and leaflets
- Survey on rare and complex epilepsies plan
- Plan for face-to-face meeting with patient representatives in 2025.

We'd like to thank all the participants in their interest and active involvement, and would like to announce the follow up meeting planned for late August 2024! For more information please contact [epag.epicare@gmail.com](mailto:epag.epicare@gmail.com).

### 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-care.eu](mailto:info@epi-care.eu) / [l.roig@epi-care.eu](mailto:l.roig@epi-care.eu)

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