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# **April 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 if you want to **forward** this newsletter... and here is the <u>link to sign up</u> and receive it every month!

#### 2024 EpiCARE Annual Meeting

In June (17<sup>th</sup> – 19<sup>th</sup>) the 7<sup>th</sup> annual meeting of the ERN EpiCARE will take place at the Hospital Sant Joan de Déu (coordinating HCP) in Barcelona, Spain.
On Monday, the face-to-face meeting of the Executive Committee will be followed by meetings of our Working Groups. The day of Tuesday is reserved for the General Assembly, with the participation of representatives from all full or affiliated EpiCARE members and collaborating partners, as well as patient advocates. The invited scientific lecture on "Brain organoids as a model in developmental epilepsy", will be given by Sandra Acosta (University of Barcelona). The afternoon is reserved to brainstorming on levels of epilepsy care at national level, the JARDIN project funded by the European Commission, and the Guidelines under preparation focusing on "Pharmacological and non-pharmacological interventions in the treatment of Infantile Epileptic Spasms syndrome". Other Working Groups and the patient advocates will meet on Wednesday morning.

### **NEXT WEBINAR**

Thursday May 16th - 17h CET Epilepsy in primary immunodeficiencies

Presented by: Katarzyna Kotulska-Jóźwiak

Register here

Our webinars take place **once a month**, and the replays are always available on our website. You can check the programme of the upcoming webinars and register to the mailing on the EpiCARE webpage:

Webinars webpage

# LATEST NEWS

**EPIPED Course was a success!** 

EDUCATIONAL WEBINARS

**EpiCARE** 

FREE TO ACCESS

REGISTRATION NECESSARY

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EPIPED Course on Treatment Strategies in Paediatric Epilepsies proved once again being very much appreciated, with almost 80 participants, mentors and mentees, adult and child neurologists from 15 different countries! The course allowed attendees to discuss with experts about the best clinical practices and therapeutic strategies. This is

the <u>session programme</u> we enjoyed! This was the 1<sup>st</sup> year of the 3 years training cycle (2024-2026), held in **Girona**, a beautiful and sunny city in Catalunya, Spain. Professors **Alexis Arzimanoglou**, **Jaume Campistol Plana**, **and Maša Malenica** have been the course directors. The training course had the endorsement of ERN EpiCARE, ILAE Europe and other scientific societies. We enjoyed **plenary sessions** on relevant topics, as well as **practical training sessions** where participants were able to discuss use cases and situations related to treatment strategies in pediatric epilepsies. Moreover, we were able to enjoy networking in this lovely place.

#### 17th Paros Epilepsy Workshop

Epilepsy surgery has been relying on anatomo-clinical correlation for more than a century and much knowledge has been accumulated, in particular since the advances of long-term video-EEG monitoring. With the recent worldwide deployment of Stereo-EEG, fine correlations have progressed further, as well as our understanding of their potential bias, ambiguities and limitations. During 5 days, 52 systematic reviews focusing on anatomo-clinical correlations of focal seizures were presented by 68 contributors from all over the world. Attended on site by another 112 experts and followed remotely by more than 300 clinicians.



#### European Joint Programme on Rare Diseases: deadline extended

The registration deadline for the Final EJP RD Conference has been extended to **May 22<sup>nd</sup>**, **2024!** Join us on **May 27-28**, **2024** for engaging sessions on rare disease research. Check out the **agenda** for a sneak peek into the sessions and plan your conference experience! <u>Register here</u> and for more information.



#### MAY

#### 17th EILAT Conference on New Antiseizure Medications - Madrid, Spain. Dates: 5 – 9 May

<u>17th EILAT Conference on New Antiseizure Medications</u> will feature discussions and information related to **new antiepileptic drugs in various stages of development**, as well as to present new findings on second-generation treatments. After the success of the 2014, 2016, 2018 and 2022 conferences held in **Madrid** (Spain), they have decided to hold the 2024 congress there again. Here is the <u>registration link</u>. The topic of "*ADDRESSING CHALLENGES WITH EPILEPSY TRIALS IN EUROPE*"

will be treated by the European Consortium for Epilepsy Trials (ECET: <u>https://epicare.eu/ecet/</u>) at the Monday May 6th morning session.

#### 18th ICNA International Child Neurology Congress - Capetown, Southafrica. Dates: 6 – 10 May

The 18th International Child Neurology Conference in 2024 "Footprints to the Future" will be held in Cape Town, South Africa, from May 6-10. Child neurology has a severely under-resourced base of expertise across the African continent, a region where 40% of the children are expected to live by 2050. The aim of this event is to provide an overview of childhood neurological disorders, from major advances to basic issues, in a way that they will be relevant to regions around the world.



# 12th European Conference on Rare Diseases & Orphan Products (ECRD 2024) EURORDIS - Brussels, Belgium. Dates: 15-17 May

EURORDIS is a conference that will take place on 15 and 16 May 2024 online and at The Square in Brussels. The ECRD is the largest, patient-led, rare disease policy-shaping event held in Europe. With over 1000 participants, the Conference is an opportunity to network and exchange insights within the rare disease community. On-site attendance is already full, but online registration is still available.



#### Tagliacozzo Training Course - Rome, Italy. Dates: 21-25 May

Specialists in neurology, psychiatry, neuropsychiatry, pediatric neurology, pediatrics, clinical neurophysiology and psychology will participate in the <u>11th International Course</u> on <u>Drug Resistant Epilepsies</u>. The programme will feature **lectures from expert epileptologists** and **working groups with tutors**, and it will be held in the St Francis Convent of Tagliacozzo, a convent built in 1115!

#### <u>JUNE</u>

With this calendar we would like to inform you briefly about the events of June:

					1	2
3	4	5	6	7	8	9
10	11	12	13	14	15	16
17 EpiCARE General Assembly (Annual Meeting) (Barcelona)	18 EpiCARE General Assembly (Annual Meeting) (Barcelona)	19 EpiCARE General Assembly (Annual Meeting) (Barcelona)	20	21	22	23
24	25	26	27	28	29 EAN (European Academy of Neurology) (Helsinki, Finland)	30 EAN (European Academy of Neurology) (Helsinki, Finland)

## **EpiCARE SCIENTIFIC PUBLICATIONS**

- Frauscher B, Mansilla D, Abdallah C, Astner-Rohracher A, Beniczky S, Brazdil M, Gnatkovsky V, Jacobs J, Kalamangalam G, Perucca P, Ryvlin P, Schuele S, Tao J, Wang Y, Zijlmans M, McGonigal A. Learn how to interpret and use intracranial EEG findings. Epileptic Disord. 2024;26(1):1-59. doi: 10.1002/epd2.20190. LINK
- Ancora C, Ortigoza-Escobar JD, Valletti MA, Furia F, Nielsen JEK, Møller RS, Gardella E. Emergence of lingual dystonia and strabismus in early-onset SCN8A self-limiting familial infantile epilepsy. Epileptic Disord. 2024;26(2):219-224. doi: 10.1002/epd2.20203. LINK.



You can consult recent publications on rare and complex epilepsies, epilepsy surgery and other topics on our <u>scientific publications webpage</u>.

EpiCARE members: please remember to mention EpiCARE in your affiliations or in the acknowledgements / references when appropriate.

# A WORD FROM OUR ePAGs

#### Different faces of rare and complex epilepsies

"It is our pleasure to announce the second conference titled DIFFERENT FACES OF RARE AND COMPLEX EPILEPSIES, organised by Dravet syndrome Croatia, that will be held in Split, Croatia at hotel Amphora from Thursday 17th to Saturday 19th of October 2024. The conference aims to encourage knowledge sharing and productive discussions on rare and complex epilepsies, and it will be hybrid, both in person and online. On 18th of October, panel discussions will be held for healthcare professionals in English, and on 19th of October panel discussion will be held in Croatian. For more information, <u>visit its</u> <u>website</u>."



#### **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

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