



# EpiCARE

## FEBRUARY 2023 NEWSLETTER

The goal of our newsletter is to keep you informed about actions related to the European Reference Network on rare and complex epilepsies, EpiCARE.

You will find information about our next events, educational and research activities and calls, but also news from the coordination team, our different members and our ePAG community.

## NEXT WEBINARS

Learn more about rare and complex epilepsies every 2nd and 4th Thursday of the month



Thursday March 2nd  
17h CET

MetabERN introduction

Maurizio Scarpa,

François Eysken

&

Angels Garcia-Cazorla

[Register](#)

Thursday March 16th  
17h CET

Seizures and EEG abnormalities in  
newborn errors of metabolism

Monika Eisermann

&

Co-speaker TBD

[Register](#)

You can check the programme of the upcoming webinars and register to the webinar mailing on the EpiCARE webinars webpage:

[Webinars webpage](#)

## LATEST NEWS

[Today is Rare Diseases Day!](#)



Rare is more than 300 million people living with a rare disease around the world.

- 72% of rare diseases are genetic
- 70% of those genetic rare diseases start in childhood

EpiCARE is one of 24 [European Reference Networks](#) focusing on rare diseases, working towards more equitable access to diagnosis, more treatment options, and overall better care.

We thank our members and colleagues for their amazing work and dedication!


## Webinar on the challenges in epilepsy clinical trials in Europe

**LIVE WEBINAR | MARCH 14 - 2023 | 4 P.M. CET**


**THE CHALLENGES WITHIN EPILEPSY TRIALS IN EUROPE**

**SPEAKERS & HOST**


**Prof. Jacqueline French**  
**Prof. Alexis Arzimanoglou**  
**Prof. Eugen Trinka**  
**Dr. Lieza Exalto**




PROF. FRENCH  
SPEAKER



PROF. ARZIMANOGLLOU  
SPEAKER



PROF. TRINKA  
SPEAKER



DR. EXALTO  
HOST



Save the date: Tuesday, March 14th, 2023 - 4:00 PM (CET)

Live webinar "The challenges within Epilepsy trials in Europe"

In collaboration with [ECET \(European Collaboration for Epilepsy Trials\)](#).

During this webinar, hosted by Dr. Lieza G. Exalto, Prof. Jacqueline French, Prof. Alexis Arzimanoglou and Prof. Eugen Trinka will discuss:

- › Experiences of the US Epilepsy Consortium
- › What is the role of European Reference Network EpiCARE in Epilepsy Trials
- › The added value of the European Collaboration for Epilepsy Trials (ECET) consortium

[Register now](#)

## EVENTS

### Dravet conference - March 23rd

Dravet Syndrome Foundation Spain organises a new edition of the Dravet Syndrome Conference, which will take place on Thursday 23rd of March 2023 in Madrid, Spain.



With the scientific endorsement of:



European Reference Network  
EpiCARE

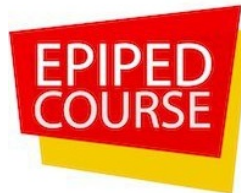
**DATE**  
Thursday 23 March, 2023

**PLACE**  
Madrid, Spain

REGISTRATION AT NO COST AT  
[www.dravetconference.com](http://www.dravetconference.com)

During the conference, presentations will include the latest advances and updates in the management and treatment of Dravet syndrome, including both new available drugs and treatments in development.

Register



**GIRONA**  
**TREATMENT STRATEGIES IN PEDIATRIC EPILEPSIES**  
A 3 years' cycle, international interactive training course



Sant Joan de Déu  
Barcelona - Hospital



EPIPED : treatment strategies in pediatric epilepsie - April 26-29

The aim of the 3 year cycle EPIPED Treatment is to reduce the geographical and knowledge gap by providing neurologists and child neurologists involved in epilepsy care the opportunity for a regular update on best treatment practices.

Topics treated are related to pharmacology, pharmacodynamics, pharmacokinetics, genetics, analysis of AED trials, design of clinical trials, pre surgical evaluation, optimal choice of AEDs, review of existing guidelines (ILAE, NICE, other), data on ketogenic diet, neurostimulation, indications for resective and palliative surgery, pharmacological treatments other than with AEDs, update on the development of targeted therapies. This link gives you access to the [full program of the 3 year cycle](#).



28th European Society Paediatric Neurosurgery - Rome, May 7th-10th

It is with honor and pleasure that I invite you to join the 28th Biennial Congress of the European Society for Pediatric Neurosurgery (ESPN), which will be held in Rome, Italy, from May 7th to May 10th, 2023.

Hot topics will be the ones of extensive large interest in practice and debates including Posterior Fossa Tumors, Craniosynostoses, Hydrocephalus. A joint venture has been established with the Brazilian Society for Pediatric Neurosurgery, with which a round table will be organized on the management of non lesional epilepsy and with the Indian Society for Pediatric Neurosurgery, again with a dedicated round table discussion, this time on Complex Congenital spine anomalies.

Prof. Dr. Gianpiero Tamburrini - ESPN President 2021-2023

[See the programme here.](#)

## SAVE THE DATE



**EpiCARE**

13<sup>th</sup> ILAE  
School for Neuropathology  
and Epilepsy Surgery

**INES 2023 VIENNA**

**August 24-26, 2023**

Medical University Vienna,  
Allgemeines Krankenhaus (AKH)  
Währinger Gürtel 18-20  
1090 Vienna

WORLD'S  
BEST  
HOSPITALS  
TOP 25  
WORLDWIDE

### 13th ILAE School for Neuropathology and Epilepsy Surgery - Vienna

Lectures and hands-on in Epilepsy Surgery, Neuropathology and Neuroanatomy.

#### Learning Objectives:

Demonstrate working knowledge of etiologies for focal and generalized epilepsy pathologies and surgical indications and approaches in children and adults (ILAE curriculum Levels 1-3)

For more information, please contact [Lisa Gäcklein](#).



#### Other upcoming events:

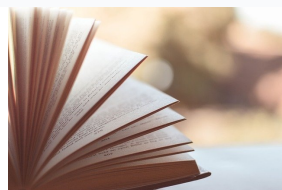
- 23 February - 25 June 2023: International Online Course on Pathogenesis of Epilepsy. [More info](#)
- 7 March : ASA-BI-NESS webinar "Making Clinical Trial Design and Analysis Robust" . [More info](#)
- 11 March: 3rd international conference on KCNB1. [More info](#)
- 23 March: Workshop on Advanced Research Methods (WARM) "Bayesian Analysis: An Overview". [More info](#)
- 23-25 March: 4th ERN-RND Winter School on Neuroimaging. [More info](#)
- 20 June: EPNS Pre-congress. [More info](#)
- 20-24 June: 15th congress of the European Paediatric Neurology Society. [More info](#)
- 1-4 July: 9th Congress of the European Academy of Neurology. [More info](#)
- 17-28 July : San Servolo Epilepsy Course "Early pediatric onset epilepsies: from syndrome and management to future perspectives". [More info](#)
- 2-6 Sept : 35th International Epilepsy Congress in Dublin, Ireland. [More info](#)

## EpiCARE SCIENTIFIC PUBLICATIONS

- Bishop, K. I., Isquith, P. K., Gioia, G. A., Knupp, K. G., Scheffer, I. E., Nabbout, R., Specchio, N., Sullivan, J., Auvin, S., Helen Cross, J., Guerrini, R., Farfel, G., Galer, B. S., & Gammaitoni, A. R. (2023)  
Fenfluramine treatment is associated with improvement in everyday executive function in preschool-aged children (< 5 years) with Dravet syndrome: A critical period for early neurodevelopment. *Epilepsy & behavior* : E&B, 138, 108994. [Link](#)
- Meritam Larsen, P., Wüstenhagen, S., Terney, D., Gardella, E., Aurlen, H., & Beniczky, S. (2023).  
Duration of epileptic seizure types: A data-driven approach. *Epilepsia*, 64(2), 469–478 [Find the publication here, in open-access](#)



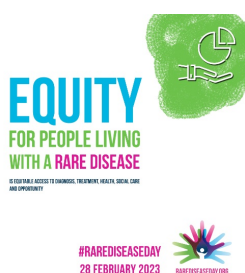
- Welniarz, Q., Gras, D., Roubertie, A., Papadopoulou, M. T., Panagiotakaki, E., & Roze, E. (2023)  
Oxygen Therapy: An Acute Treatment for Paroxysmal Dystonia in Alternating Hemiplegia of Childhood? Movement disorders : official journal of the Movement Disorder Society, 10.1002/mds.29357. Advance online publication.[Link](#).



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.

## A word from our ePAGs



### Rare disease day

Today we celebrate the day dedicated to all rare diseases!

Among our EpiCARE Network we distinguish more than 130 rare and complex epilepsies, but besides our diversities we share many common grounds that highly affect the quality of life of all patients!

Our ultimate goal is equality, equality in access to diagnosis, treatment, health and social care! Only together we can achieve this for our patients across Europe! Join us!



### International Epilepsy Day

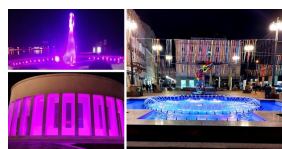
This year's theme for International Epilepsy Day (13 February), "Step Up Against Stigma", provided a platform for people with epilepsy, and those who care for them, to dispel myths with facts. Educating people about epilepsy and dispelling myths can reduce stigma and discrimination at school, at work, in the clinic, across the community and at home.

International Epilepsy Day is celebrated in more than 100 countries. It is estimated that more than 50 million people are living with epilepsy

around the world. The provision of safe, effective, and highly affordable (\$5 per person/year) anti-seizure medicines could control seizures in up to 70% of people with epilepsy. On the other hand, around 30% of epilepsy patients have drug resistant epilepsy which limits the effects of the treatments as well as the quality of life. Epilepsy ranks among the top five causes of global neurological disability; an estimated 125,000 deaths per year globally are related to the condition. Untreated epilepsy is a life-threatening disorder.

The death rate for people with epilepsy is three times that of the general population, and for some specific syndromes even higher. Every fourth case of epilepsy could be prevented by addressing and minimizing risk factors, such as stroke, brain infections, birth injuries, and head trauma. However, prevention strategies remain limited and underexplored. People with epilepsy are disproportionately affected by other conditions as well, such as depression, anxiety, dementia, migraine, heart disease, peptic ulcers, and arthritis. Many more additional conditions affect the ones with rare and complex epilepsies.

In Croatia it is already a tradition to highlight the Awareness Day with purple lights across the country!



### SCN8A Awareness Day

On the 9th of February, we celebrated International SCN8A Awareness Day! At this date, the SCN8A European Federation was officially established! This date was chosen for many reasons, including the Awareness day as well as celebrating and honouring Shay and her life, the first known case of SCN8A who unfortunately passed away before her father's discovery. Congratulation on the new European Federation, and we look forward to your future work for SCN8A patients!

### Angelman syndrome Awareness Day

On February 15th, 10th International Angelman syndrome Awareness Day was celebrated!

The purpose of marking day is to: raise awareness worldwide of the condition, mobilise people to action & encourage fundraising for the AS organisation in their country, promote research and educational resources in the organisation's own country and remember those people with Angelman Syndrome who are no longer with us.



### SCN2A Awareness day

SCN2A is located on chromosome 2 at position 24 hence 24th of February was picked to celebrate the awareness day!

Symptoms of this complex conditions vary and can include: hypotonia, seizures, breathing difficulties, intellectual disability and autistic features.

There is no cure for this condition yet, but clinical trials are undergoing!





Fist ePAG EpiCARE newsletter published!

ePAG EpiCARE is establishing a Newsletter dedicated to patients' associations dedicated to rare and complex epilepsies with the first edition published on February 14th.

If you are a patients' association and wish to disseminate the information about your association, projects, activities and events you are planning, please contact:

[epag.epicare@gmail.com](mailto:epag.epicare@gmail.com)

If you wish to receive news from ePAG EpiCARE [subscribe here](#).

## 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

[a.robert@epi-care.eu](mailto:a.robert@epi-care.eu)

Follow us on social media!



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