



EpiCARE

MARCH 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 30th
17h CET

Treatable epilepsies due to inborn
errors of metabolism

Barbara Plecko

[Register](#)

Thursday April 13th
17h CET

Neuronal ceroidlipofuscinosis from
clinical findings to treatments on
pipeline

Nicola Specchio

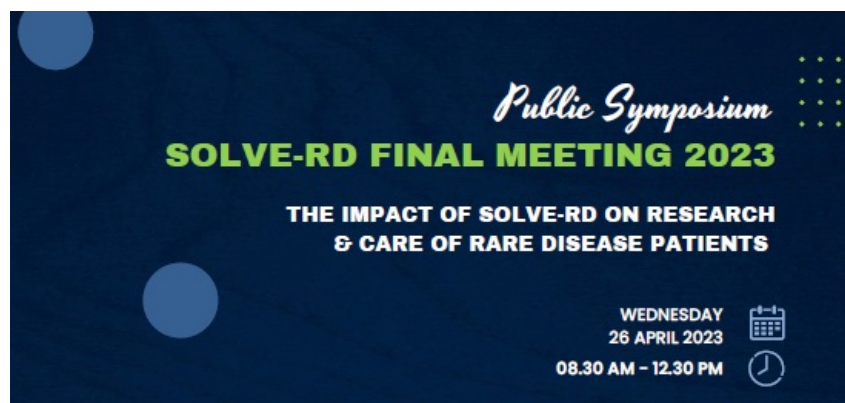
[Register](#)

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

[Webinars webpage](#)

LATEST NEWS

[SOLVE-RD Public symposium](#)



Public Symposium at the Solve-RD Final Meeting 2023: The Impact of Solve-RD on Research & Care of Rare Disease Patients

Date: Wednesday, 26 April 2023 from 8:30-12:30 CEST, online

[Registration](#)

[Download the full programme here.](#)

EVENTS



EPIPED : treatment strategies in pediatric epilepsy - 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.

See the [full program of the 3 year cycle.](#)

Bonn Epilepsy Seminar



bonner epilepsie seminar

The Summer programme of the Bonn Epilepsy Seminar is out!

Wed, 10. May, 16:00 - 17:30: The spectrum of SCN8A-related epilepsy
Prof. Rikke Möller Department of Epilepsy Genetics and Personalized Medicine,
Danish Epilepsy Centre, Filadelfia / University of Southern, Denmark

Wed, 24. May, 16:00 - 17:30: Inflammatory pathways as diagnostic markers and

therapeutic targets in epilepsy
Prof. Annamaria Vezzani Department of Neuroscience, Istituto di Ricerche
Farmacologiche Mario Negri IRCCS, Milano, Italy

Wed, 14. June, 16:00 - 17:30: Pediatric epilepsy syndromes that adult neurologists should know

Prof. Alexis Arzimanoglou, Department of Paediatric Clinical Epileptology, Sleep Disorders and Functional Neurology, University Hospitals of Lyon, France

Wed, 21. June, 16:00 - 17:30: Novel computational approaches to understand generation and propagation of seizures

Dr. Yujiang Wang, PhD CNNP Lab, Interdisciplinary Computing and Complex BioSystems Group, School of Computing, Newcastle University, UK

[More information](#)



- 23 February - 25 June 2023: International Online Course on Pathogenesis of Epilepsy. [More info](#)
- May 7-10: 28th European Society Paediatric Neurosurgery [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](#)
- 24-26 August: 13th ILAE School for Neuropathology and Epilepsy Surgery.
- 2-6 Sept : 35th International Epilepsy Congress in Dublin, Ireland. [More info.](#)

EpiCARE SCIENTIFIC PUBLICATIONS

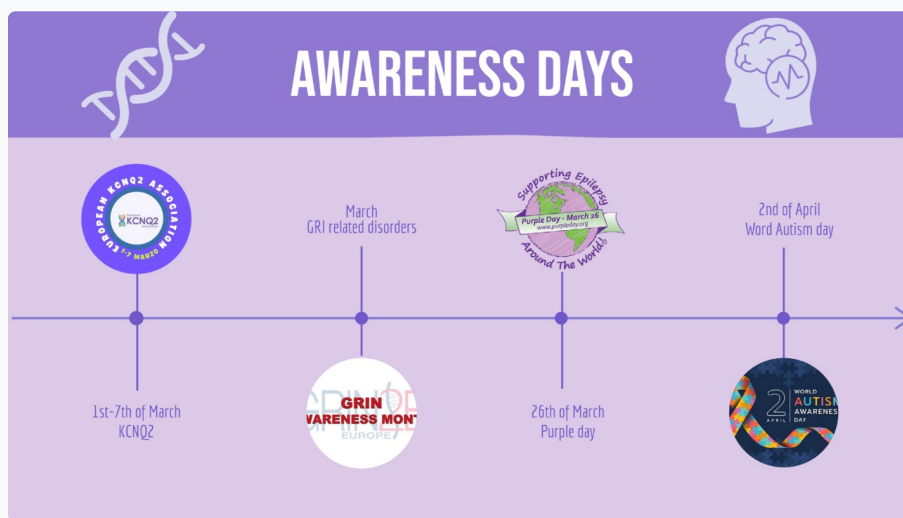
- Neal, A., Bouet, R., Lagarde, S., Ostrowsky-Coste, K., Maillard, L., Kahane, P., Touraine, R., Catenio, H., Montavont, A., Isnard, J., Arzimanoglou, A., Hermier, M., Guenot, M., Bartolomei, F., Rheims, S., & Jung, J. (2022). Epileptic spasms are associated with increased stereo-electroencephalography derived functional connectivity in tuberous sclerosis complex. *Epilepsia*, 63(9), 2359–2370. [Link](#)
- Sourbron, J., Auvin, S., Arzimanoglou, A., Cross, J. H., Hartmann, H., Pressler, R., Riney, K., Sugai, K., Wilmshurst, J. M., Yozawitz, E., & Lagae, L. (2023). Medical treatment in infants and young children with epilepsy: Off-label use of antiseizure medications. Survey Report of ILAE Task Force Medical Therapies in Children. *Epilepsia open*, 8(1), 77–89. [Link](#) (open access)
- Nababout, R., Kuchenbuch, M., Tinuper, P., Cross, J. H., & Wirrell, E. (2023). 3D figure of epilepsy syndromes. *Epilepsia open*, 8(1), 217–220. [Link](#)
- Peltola, M. E., Leitinger, M., Halford, J. J., Vinayan, K. P., Kobayashi, K., Pressler, R. M., Mindruta, I., Mayor, L. C., Lauronen, L., & Beniczky, S. (2023). Routine and sleep EEG: Minimum recording standards of the International



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



New leaflet published!

New leaflet for healthcare professionals and patients and caregivers is dedicated to Rett syndrome. You can [view and download the leaflet here](#).

We thank Rett Syndrome Europe, and Dr. Aglaia Vignoli for investing your time in the preparation of these documents, as well as to ERN ITHACA for their contribution!

Information for Healthcare Professionals



Rett syndrome

Also known as: RTT



ePAG EpiCARE newsletter

ePAG EpiCARE is establishing a Newsletter dedicated to patients' associations dedicated to rare and complex epilepsies.

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

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

Follow us on social media!



Our mailing address is:

Department of Paediatric Clinical Epileptology, Sleep Disorders and Functional Neurology
ERN EpiCARE c/o Pr Arzimanoglou
Hôpital Femme Mère Enfant (HFME)
59 Boulevard Pinel
69677 Bron, FRANCE

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