

EpiCARE MARCH 2021 NEWSLETTER

Welcome to our new newsletter which aims 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 every second Thursday of the month with EpiCARE!



MECP2: Rett Sd and beyond

Presented by Giangennaro Coppola & Alessandra Renieri Thursday, 15th April 2021

Register

LATEST NEWS



We are pleased to present the NEW EpiCARE logo

It has been redesigned by Marc Chaperon in collaboration with the management team and you, the members of the network!

We are also currently in the process of updating our website. A new "For patients" section has been created. In it, patients will be able to find all the answers to their questions. Soon, a "For clinicians" section will be created to allow health professionals to find all the information concerning them and the EpiCARE network.

Get to know your EpiCARE team members!

Sébile Tchaicha has joined the coordination team in December. She will help to the development of research project, be involved in the EJPRD project and take part to the development of our European registries. Besides working for EpiCARE, Sébile is the study coordinator of the Department of Paediatric Clinical Epileptology of Prof. Arzimanoglou and the Department of Adult Functional Neurology and Epileptology of Prof. Rheims at Hospices Civils de Lyon. She has a master's degree in fundamental and clinical neuroscience and was specialized in cognitive



EDUCATION & TRAINING



Online courses available

Thanks to a CEF Telecom project co-funded by INEA Agency of the European Union, healthcare professionals can obtain and increase essential and clinically relevant knowledge, skills, and competencies in the field of epilepsy through <u>a series of online interactive courses</u> in close collaboration with the <u>ILAE</u>.

ERN EXCHANGE PROGRAMME 2021-2022

Launched by the European Commission in cooperation with ECORYS, this program aims to share knowledge and stimulate collaboration between health care professionals in European Reference Networks (ERN).

EpiCARE is involved in this programme and has 44 exchange packages to spend during the three editions (March - August 21 / September 21 - Feb 22 / March 22 - August 22). Get more information by reading this <u>document</u>.

EPAG

New call



The Associazione Sindrome Sturge Weber Italia Onlus was founded in 2016 by the desire of some families, with children affected by Sturge Weber syndrome, to join in a network of solidarity.

The association announces a competition for 2021 for the allocation of a fund to research projects in the field of basic sciences and clinical research in specialities related to Sturge-Weber syndrome.

In case of interest, by connecting to this link, you can download the announcement and the project form to fill in and send it back to the association. If necessary, specific questions can be addressed to

info@sturgeweberitalia.org

Lighting of the arena of Verona (Italy)

The arena in Verona has been illuminated on the occasion of the International



Epilepsy Day and the World Rare Disease Day, organised by Dravet Italia Onlus - EpiCARE ePAG - Isabella Brambilla - with also Azienda Ospedaliera di Verona (Verona Hospital) with the Child Neuropsychiatry Team.

Watch the video here.

EVENTS

EpiCARE annual meeting: SAVE THE DATE!



The 2021 EpiCARE annual meeting will be virtual!

To facilitate interaction and quality of attendance the Steering Committee privileged splitting it into 3 afternoon sessions and avoid full-day sessions. The sessions will start on Wednesday 24th, Thursday 25th and Friday 26th of March. The annual meeting is open only to

The annual meeting is open only to EpiCARE members and staff of the cooperating partners of EpiCARE.

Download the program here.

EpiCARE SCIENTIFIC PUBLICATIONS

We share below the latest collaborative works of our members

"Children with temporal lobe epilepsy are more likely to achieve sustained seizure freedom and withdraw of medication when referred early to specialised epilepsy-surgery team"

Barba, C., Cossu, M., Guerrini, R., Di Gennaro, G., Villani, F., De Palma, L., Grisotto, L., Consales, A., Battaglia, D., Zamponi, N., d'Orio, P., Revay, M., Rizzi, M., Casciato, S., Esposito, V., Quarato, P. P., Di Giacomo, R., Didato, G., Pastori, C., Pavia, G. C., ... Tassi, L. (2021). Temporal lobe epilepsy surgery in children and adults: A multicenter study. Epilepsia, 62(1), 128–142. https://doi.org/10.1111/epi.16772

The International League Against Epilepsy (ILAE) presents a new classification and framework for seizures in the neonatal period in line with 2017 ILAE classifications.

Pressler, R. M., Cilio, M. R., Mizrahi, E. M., Moshé, S. L., Nunes, M. L., Plouin, P., Vanhatalo, S., Yozawitz, E., de Vries, L. S., Puthenveettil Vinayan, K., Triki, C. C., Wilmshurst, J. M., Yamatomo, H., & Zuberi, S. M. (2021). The ILAE classification of seizures and the epilepsies: Modification for seizures in the neonate. Position paper by the ILAE Task Force on Neonatal Seizures. Epilepsia, 10.1111/epi.16815. Advance online publication. https://doi.org/10.1111/epi.16815

More publicatios on our website.

Message to the EpiCARE medical teams and ePAG: share with us information on activities you estimate we could include in upcoming issues of our newsletter at epicare.website@gmail.com















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