

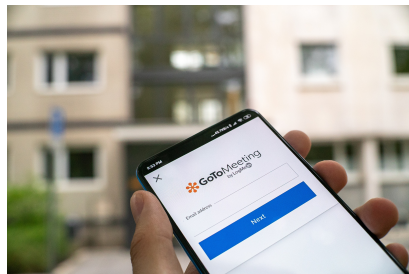


EpiCARE JANUARY 2021 NEWSLETTER

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



[Non Adherence to treatment in epilepsy](#)

By Oliver Henning

Thursday, 14th January 2021

Learn more every second Thursday of the month with EpiCARE!

Non-adherence to anti-seizure drug treatment can result in seizure relapse, status epilepticus, hospital admissions, increased healthcare costs and possibly SUDEP. Knowledge of risk factors for both intentional and unintentional non-adherence are important to ensure adequate antiseizure treatment.

[View the recording](#)

LATEST NEWS

[400.000 euros to support research project about Alternating Hemiplegia of Childhood](#)

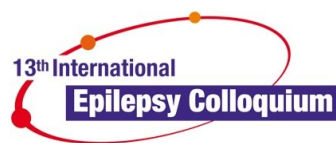
Alternating Hemiplegia of Childhood: The San Juan de Dios Child Neurology Dpt. (Barcelona) and the Lyon (HCL) Paediatric Epilepsy Dpt., both full members of EpiCARE, together with the Section of Genomic Medicine (Catholic University of Rome) and the Child Neuropsychiatry Unit of the Instituto Gaslini (Genova), supported by [AISEA](#) and [AESHA](#) patients associations, raised nearly 400.000 Euros to support a research project in one of the very rare diseases associating epilepsy and disorders of movement, Alternating Hemiplegia of Childhood. All teams are also members of the [International Consortium for Research in AHC](#) managed by Dra Rosaria Vavassori,

EDUCATION & TRAINING



Online courses soon available

Did you know that the working package on Education and training of EpiCARE is working on a series of online interactive courses in close collaboration with the ILAE? You can already check the [ILAE Academy website](#) and the EpiCARE courses will be available soon on www.epi-care.eu thanks to a CEF Telecom project co-funded by the EU.



Epilepsy Colloquium

In light of the uncertain months ahead, the 13th International Epilepsy Colloquium will transition to a digital event in May 20-22, 2021. Today, more than ever, the goal of this colloquium is to bring together worldwide leaders involved in epilepsy to discuss new results, candidate therapeutics, and methodological issues. [More information](#).



CLINICAL PATIENT MANAGEMENT SYSTEM (CPMS) UPDATES

1) The user can now select the frequency of email notifications. Originally a user that was involved in a panel would receive a daily email notifying them of their involvement, however these can now be changed. There are some notifications that will be delivered as mandatory.

2) Patient records can now be transferred to the ERN coordinator when the original user Health Care Provider or Guest Virtual Centre is to have their CPMS access deactivated or removed. This allows for the discussions to continue and support/care to still be offered to the patient. This means that data controllership is switched from the Health Care Provider or Guest Virtual Centre to the ERN coordinator centre. Consent must be gained from the patient for this to happen.

3) The new simplified workflow is in the process of being developed and tested and hopefully will be released later in 2021.

EPAG

Two other projects selected for funding by EJP RD



- 1) EJPRD2020-071 SCN1A-UP
Therapeutic strategies for Dravet syndrome: upregulation of endogenous SCN1A and modulation of

remodeling.
Coordinator: Prof. Massimo Mantegazza (IPMC, Antipolis, France)
ePAG representative: Isabella Brambilla, member of the EpiCARE Steering Committee

2) EJPRD20-05 TREATKCNQ
Targeted treatment for KCNQ related encephalopathies: retigabine analogues, repurposed drugs and allele specific knock down.
Coordinator: Prof. Weckhuysen, Sarah (Antwerp University Hospital, Belgium)
ePAG representative: Isabella Brambilla, member of the EpiCARE Steering Committee

PARTNERS EVENT

50 Million steps for Epilepsy



Join or organise a walk and help us walk 50 million steps – a step for every person affected by epilepsy in the world. Starting on Monday, January 4th and ending on International Epilepsy Day 2021 – Monday February 8th, we're walking to raise awareness, to improve visibility and increase understanding of epilepsy. This is an initiative created by the International Bureau for Epilepsy (IBE) and the International League Against Epilepsy (ILAE).

Are you up for the challenge? [More info](#)

EpiCARE SCIENTIFIC PUBLICATIONS

We share below the latest collaborative works of our members

"Epilepsy develops in 70 to 90% of children with tuberous sclerosis complex (TSC) and is often resistant to medication. Recently, the concept of preventive antiepileptic treatment to modify the natural history of epilepsy has been proposed. EPISTOP was a clinical trial designed to compare preventive versus conventional antiepileptic treatment in TSC infants".

- Kotulska, Katarzyna et al. "Prevention of Epilepsy in Infants with Tuberous Sclerosis Complex in the EPISTOP Trial." *Annals of neurology*, 10.1002/ana.25956. 12 Nov. 2020, doi:10.1002/ana.25956

Link here: <https://doi.org/10.1002/ana.25956>

"This European multicentre randomised controlled trial is designed to compare the effects of corticosteroids and clobazam on cognitive functioning after 6 months. Secondary outcomes include cognitive functioning after 18 months, EEG abnormalities in sleep, safety and tolerability, and seizure frequency. We also aimed at investigating whether treatment response in epileptic encephalopathy with ESES can be predicted by measurement of inflammatory mediators and autoantibodies in serum."

- van den Munckhof, Bart et al. "Corticosteroids versus clobazam in epileptic encephalopathy with ESES: a European multicentre randomised controlled clinical trial (RESCUE ESES*)." *Trials* vol. 21, 1957. 23 Nov. 2020, doi:10.1186/s13063-020-04874-2

Link here: <https://doi.org/10.1186/s13063-020-04874-2>

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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