EpiCARE

SEPTEMBER 2022 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

Intracranial vascular malformations and epilepsy

October 6th at 17:00 CET

Felix Rosenow
&
Juergen Konczalla

Register

Molecular and cellular mechanisms in different MCDs

October 20th at 17:00 CET

Fiona Francis
&
Nadia Bahi-Buisson

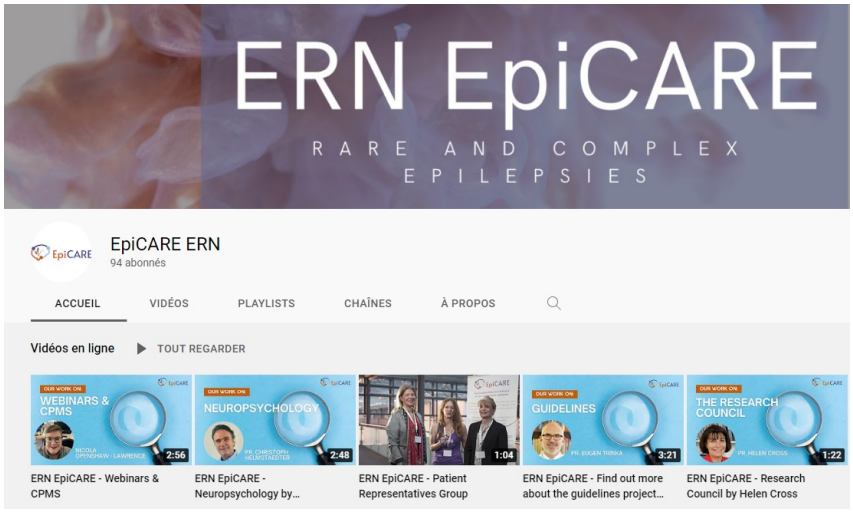
Register

On the webinar wepage, you can check out the agenda for the next webinars and subscribe to the webinars mailing to get a reminder a few days before each webinar.

Webinars webpage

LATEST NEWS

What are we working on?



We updated our Youtube channel and posted video interviews of our work group leaders : find out more about our activities and projects, from our members themselves!

EpiCARE Youtube channel

New leaflet on CDKL5, and patient journey on KCNQ2!

Thanks to the work of Carol-Anne Partridge, member of CDKL5-UK and Pr. Reetta Kalviainen, we just published a new leafet on CDKL5 Deficiency disorder.
As for the other leaflet, it contains 2 parts: one for healthcare professionnals, and one for the patient or their families and carers.

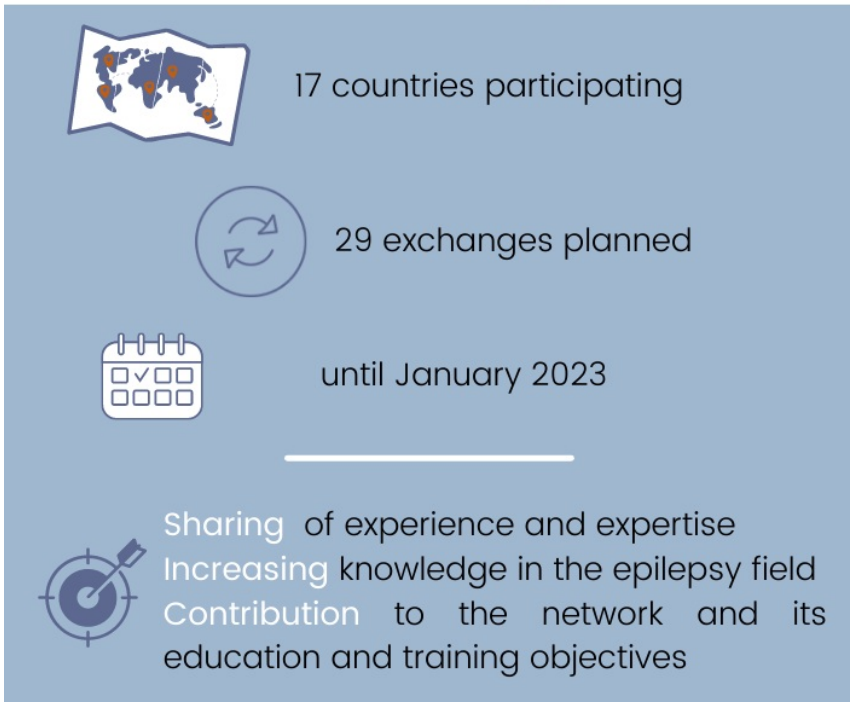
We are also glad to publish a new patient journey, on KCNQ2 ! These journeys aim to map out the pathway of patients affected by a rare epilepsy. They provide support to the family, and can be a tool to improve communication between patients/families and clinicians.

Check it out here: Rare epilepsies leaflets and patient's journeys

ERN Exchange programme

EpiCARE

Mobility Exchange Programme



We are glad to share the short promotional video of the ERN Exchange Programme. In the video, professionals of various ERNs tell about their experiences visiting or receiving colleagues of other hospitals in their Network.

The exchange programme allows professionnals from the ERN to visit other centres membres of the network, to exchange good practices and increase their knowledge, expertise and practical experience.

ERN Exchange programme video

EVENTS

IN SEARCH OF LOST TIME

3rd Rome Workshop
on rare and complex epilepsies

FROM EPILEPTOGENESIS TO CLINICAL CARE

December 13th to 15th 2022 - Rome, Italy

ILAE International League Against Epilepsy

LICE Lega Italiana Contro l'Epilessia

Bambino Gesù Ospedale Pediatrico

Endorsed by the European Reference Network for rare and complex epilepsies

EpiCARE

Rome workshop : in search of lost time - 13-15 December, Rome, Italy

The third edition of the Rome workshop "In search of lost time" is taking place this winter, from December 13th to 15th !

Find the programme here. More details on registration will be provided soon.

Great news: The 3rd Rome workshop "From Epileptogenesis to Clinical Practice" will include a full 2 hours session on "Innovative findings from early career researchers". A unique opportunity to show what you are working on, get feedback from senior experts and network.

This opportunity is part of the Exchange Program for ERNs, funded by the European Commission. Travel and accommodation will be refunded for those working at EpiCARE full and affiliated medical teams.

To submit a proposal, you need to send an e-mail to info@epi-care.eu describing your work in a few sentences before Monday October 17th.

15th congress of the European Paediatric Neurology Society - 2023

We are glad to share the news for the EPNS 2023:

"Welcome to the 15th Congress of the European Paediatric Neurology Society (EPNS)

with the main highlight “From genome and connectome to cure”. We invite you to see how the latest trends in understanding pathophysiology of neurological diseases are being implemented in clinical practice. Our field has traditionally focused on precise diagnostics; however, curative treatments were unavailable for a long time. Today, this trend is changing rapidly and novel therapeutic options in our field have brought hope to many families of children even with the most severe neurological conditions.

Learn more and SUBMIT your ABSTRACT (closes 31 December 2022):
Watch the video, less than 2 minutes
Any questions, send an e-mail

Upcoming events:

- 30 Sept: Rare Epilepsies Conference, UK
- 6-7 Oct: International congress clinical frontiers in paediatric neurology, Slovenia. More info
- 19-21 Oct: conference on Alternating Hemiplegia of Childhood and ATP1A3 diseases in Edinburgh. More info and registrations.
- 14-17 Nov: All-ePAG meeting. Programme.

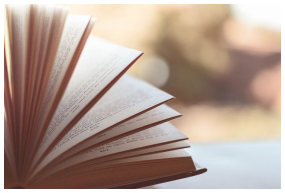
EpiCARE SCIENTIFIC PUBLICATIONS

- Juliá-Palacios, N., Molina-Anguita, C., Sigatulina Bondarenko, M., Cortès-Saladelafont, E., Aparicio, J., Cuadras, D., Horvath, G., Fons, C., Artuch, R., García-Cazorla, À., & Institut de Recerca Sant Joan de Déu Working Group (2022).
  Monoamine neurotransmitters in early epileptic encephalopathies: New insights into pathophysiology and therapy. Developmental medicine and child neurology, 64(7), 915–923. Cross-ERN publication. Link

- Sitaš, B., Bobić-Rasonja, M., Mrak, G., Trnski, S., Krbot Skorić, M., Orešković, D., Knezović, V., Petelin Gadže, Ž., Petanjek, Z., Šimić, G., Kolenc, D., & Jovanov Milošević, N. (2022)
  Reorganization of the Brain Extracellular Matrix in Hippocampal Sclerosis. International journal of molecular sciences, 23(15), 8197. Link

- Barba, C., Giometto, S., Lucenteforte, E., Pellacani, S., Matta, G., Bettiol, A., Minghetti, S., Falorni, L., Melani, F., Di Giacomo, G., Giordano, F., De Masi, S., & Guerrini, R. (2022).
  Seizure Outcome of Temporal Lobe Epilepsy Surgery in Adults and Children: A Systematic Review and Meta-Analysis.
  Neurosurgery, 10.1227/neu.0000000000002094. Link

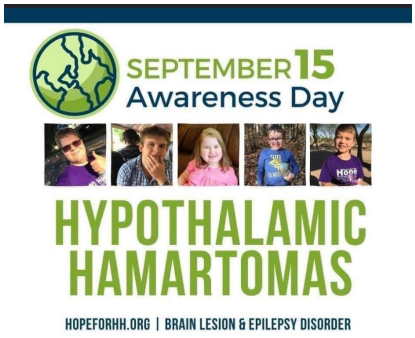
- Henning, O., Alfstad, K. Å., Johannessen Landmark, C., Helmstaedter, C., Lossius, M. I., & Holth Skogan, A. (2022).
  Use of screening tools to assess comorbidities and adverse events in patients with epilepsy. A European Reference Network for Rare and Complex Epilepsies (EpiCARE) survey.
  Seizure, 101, 237–243. Advance online publication. Link



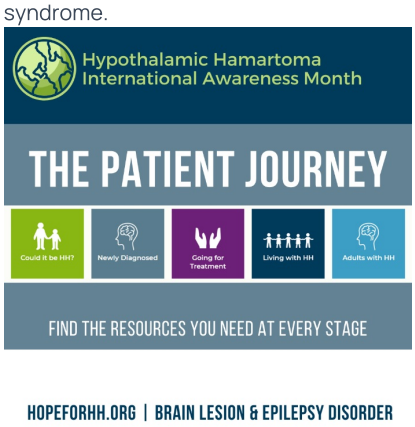
You can consult recent publications on rare and complex epilepsies, epilepsy surgery and other topics on our scientific publications webpage.

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

A word from our ePAGs



September is International Hypothalamic Hamartoma Awareness month, with the 15th September 2022 marking the 3rd annual International Hypothalamic Hamartoma (HH) Awareness Day! Hope for Hypothalamic Hamartomas UK is excited to promote this important milestone on behalf of those we serve in the HH community, and we ask you to help us be the voice for all who live with this rare and complex epileptic syndrome.

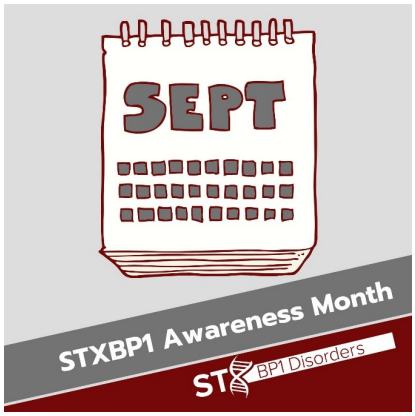


Our goal as a community is to improve the quality of life of people living with hypothalamic hamartomas (HH). Although generally characterized by rare gelastic (laughing) seizures, those living with HH understand that its symptoms are not limited to epilepsy, that the co-morbidities have an equally significant effect on quality of life, and that each individual has a unique patient journey. HH is a lifelong syndrome with challenges that change throughout the life of a patient. It requires us to continue to fund research that will lead to improved treatment and a future cure.
We strive to provide educational information and resources regarding the comorbidities associated with HH. These include endocrine dysfunction, psychiatric conditions, cognitive impairment, and sleep disturbances. Working together with the HH community we can positively impact those living with this complex and rare syndrome by raising awareness, educating our communities, and pushing for more research.
We ask that you, our epilepsy community, family and friends, to embrace this international awareness initiative throughout the month of September.
Working together we'll ensure those with HH continue to have a voice!

14th International Epilepsy Colloquium
Our patient representative Isabella Brambilla presented at the International Epilepsy Colloquium in Lausanne the following topic "Miscommunication between physicians, patients and caregivers". It was a great opportunity to understand how to improve communication and how to implement the information available to patients and carers. It was emphasised how important knowledge is to educate and lead to a path of collaboration and continuous communication with one's own physicians. Associations, patient representatives and EpiCARE can do a lot by working in synergy. The final comments of the presentation were "Given the drug-resistant epilepsies and their complexity in terms of comorbidities, the patient/caregiver is a key interlocutor in understanding/reporting the phenomena and consequently providing the experts information for an appropriate therapeutic and rehabilitation choices."
Raising and educating the patients/caregivers on what to report to physicians is fundamental, just as it is equally important that the physicians cooperate patiently and ensure that the information is understood, and that at each interview, he/she urges the patients/caregivers (there is often fear) to ask questions.

STXBP1 Disorders awareness month

September is also reserved for raising awareness about STXBP1 disorders! The STXBP1 gene is located on chromosome 9q34.1 and was discovered in 2008 in studies of some patients with Ohtahara Syndrome, a severe early onset epilepsy. Since the initial discovery, our



understanding of STXBP1 disorder has expanded, revealing a range of patient symptoms. Individuals may develop various symptoms in varying severities such as:

epilepsy, global delay, cognitive impairment, movement disorders, and autism. Changes on STXBP1 gene impair the vesicular release of neurotransmitter along the synapses. These changes are typically new in families and a single copy of a damaged gene is enough to cause the disorder.
This year STXBP1 organisations are dedicated to natural history study with the word-wide participation!

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:

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