EpiCARE

APRIL 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 May 11th
17h CET

Mitochondrial diseases and epilepsy in childhood

Tiziana Granata &
Anna Ardissone

Register

Thursday June 15th
17h CET

How to bridge the gap between trial in animals and humans

Aristea Galanopoulou &
Jacqueline French

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

2nd Rome debate on severe epilepsies

Do not miss this debate, featuring many EpiCARE members around a great topic : severe epilepsies and developmental and epileptic encephalopathies.

Discover the full programme here.

Register here - this is a hybrid meeting

EVENTS

2nd SCN2A and SCN8A Conference

The second European Conference will take place in Denmark focusing on common aspects of SCN2A/SCN8A but also highlighting their specificities: clinicians, researchers and patient advocates will have the possibility to enhance the intersection of data and expertise, enriching knowledge of optimum therapies and stimulating ideas for new research streams.

The event will pay particular attention to patient registries and Natural History Studies, but also to new areas of research to address the best precision medicine possible. EpiCARE is endorsing this event.

More information here

IInternational Epilepsy Congress 2023

Register now for the 35th International Epilepsy Congress, taking place in Dublin!

An outstanding programme with first-class education and science, with diverse topics presented in different session formats, allowing delegates to increase their knowledge and actively participate in the sessions, as well as the the latest research - posters and oral presentations. Over 80 abstracts, judged to be of the highest standard, were selected for oral presentation in Platform Sessions at IEC 2023. Presenting the very latest research findings, Platform Sessions are a must-attend!

View the programme here.

Register here : early-bird offer until May 19th!

- 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.

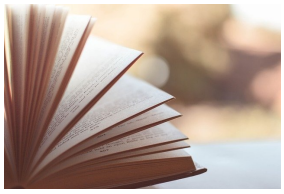
EpiCARE SCIENTIFIC PUBLICATIONS

- Balestrini, S., Doccini, V., Giometto, S., Lucenteforte, E., De Masi, S., Giarola, E., Brambilla, I., Pieroni, F., Perulli, M., Battaglia, D., Specchio, N., Ragona, F., Granata, T., Pellacani, S., Ferrari, A., Marini, C., Matricardi, S., Cesaroni, E., Giordano, L., Accorsi, P., … Guerrini, R. (2023).
  A registry for Dravet syndrome: The Italian experience. Epilepsia open, 10.1002/epi4.12730. Advance online publication. Link.

- Cossu, A., Lo Barco, T., Proietti, J., Dalla Bernardina, B., Cantalupo, G., Ghobert, L., Brambilla, I., Giarola, E., Costa, A., De Benito, T., Bethge, S., Cardot, S., Montwill, I., Remonato, E., Gramaglia, S., & Darra, F. (2023).
  Clinical characteristics of 80 subjects with KCNQ2-related encephalopathy: Results from a family-driven survey. Epilepsy & behavior : E&B, 142, 109153. Advance online publication. Link.

- Barba, C., Blumcke, I., Winawer, M. R., Hartlieb, T., Kang, H. C., Grisotto, L., Chipaux, M., Bien, C. G., Heřmanovská, B., Porter, B. E., Lidov, H. G. W., Cetica, V., Woermann, F. G., Lopez-Rivera, J. A., Canoll, P. D., Mader, I., D'Incerti, L., Baldassari, S., Yang, E., Gaballa, A., … SLC35A2 Study Group (2023).
  Clinical Features, Neuropathology, and Surgical Outcome in Patients With

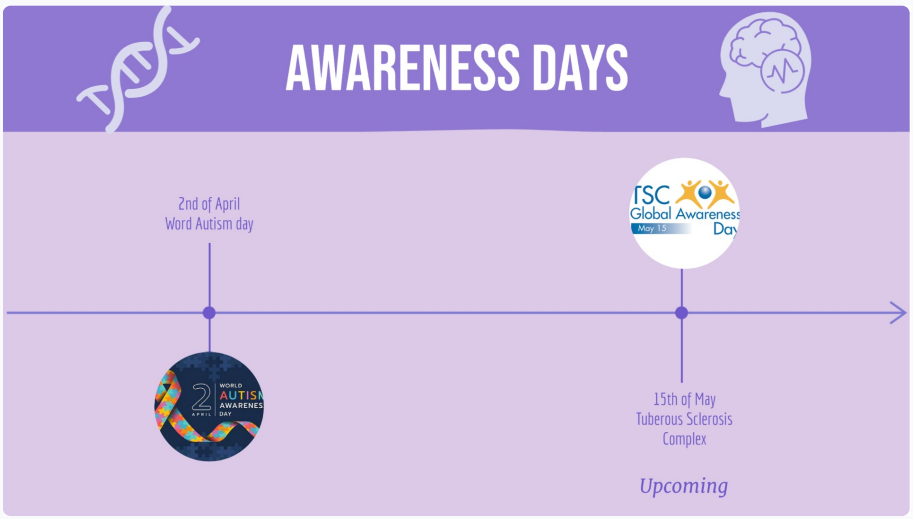
Refractory Epilepsy and Brain Somatic Variants in the SLC35A2 Gene. Neurology, 100(5), e528–e542. Link.



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



NEUROSENSE Project

This project is dedicated to finding biomarkers for predicting sudden unexpected death in epilepsy, as well as creating a prototype of SUDEP medical device for its prediction and prevention.

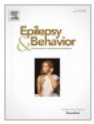
In order to design a prototype successfully, experience and perspective of patients and their families is of great help and it is recognized in this project. This is also one of the first projects for designing a prototype for predicting SUDEP, so it is very much appreciated the inclusion of patients and our opinion, experience, and practical daily life.

Every person affected with epilepsy or their caregivers can join the project by filling the survey which is completely anonymous and available in different languages (EN, PT, FR, DK, DE, IT, ES, HR). Survey is available on following link. More information about the project you can find here.

New article about KCNQ2-realted encephalopathy

The survey was developed in collaboration with caregivers from different European family associations, and was aimed at investigating the onset and frequency of epileptic seizures, anti-seizure medications (ASM), hospitalizations, stages of development, and comorbidities.
Huge gratitude to the organisations involved: Alessandra Costa, Elisa Remonato and Sara Gramaglia (European KCNQ2 Association Odv, Italy), T. De Benito (Asociación KCNQ2 España, Spain), Sebastian Bethge (KCNQ2 e.V. Germany, Germany), S. Cardot (KCNQ2 France Développement, France), Iga Montwill (KCNQ2 Poland Group, Poland) and Isabella Brambilla and Elisa Giarola (Dravet Italia Onlus, Alleanza Epilessie Rare e Complesse, Italy) for their activity and great contribution!
Article is available here (open access)

Epilepsy & Behavior
Volume 142, May 2023, 109153



Clinical characteristics of 80 subjects with KCNQ2-related encephalopathy: Results from a family-driven survey

A. Cossu [a b], T. Lo Barco [a b], J. Proietti [a b], B. Dalla Bernardina [b], G. Cantalupo [a b], L. Ghobert [a b], I. Brambilla [b c d e], E. Giarola [b c d], A. Costa [e], T. De Benito [f], S. Bethge [g], S. Cardot [h], Iga Montwill [i], E. Remonato [c e], S. Gramaglia [e], F. Darra [a b]

Article about the Italian experience with Residras – registry for Dravet syndrome and other syndromes correlated with SCN1A and PCDH19 gene mutation

The Residras registry represents a large collection of standardized national data for the DS population. It relies on a shareable and interoperable framework, which promotes multicenter high-quality data collection. In the future, such integrated platform may represent an invaluable asset for easing access to cohorts of patients that may benefit from clinical trials with emerging novel therapies, for drug safety monitoring, and for delineating natural history. Its framework makes it improvable based on growing experience with its use and easily adaptable to other rare and complex epilepsy syndromes.
Full article is available here.

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!

EpiCARE

HCL HOSPICES CIVILS DE LYON

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