



EpiCARE

EpiCARE JANUARY 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 WEBINAR

Learn more every 2nd and 4th Thursday of the month with EpiCARE!



Imaging in tuberous sclerosis

February 10th at 17:00 CET

Pavel Krsek
&
Floor Jansen (NL)

[Register now](#)

Subscribe to the **webinars mailing** to get a reminder a few days before each webinar.

[Subscribe to the webinars newsletter](#)

LATEST NEWS

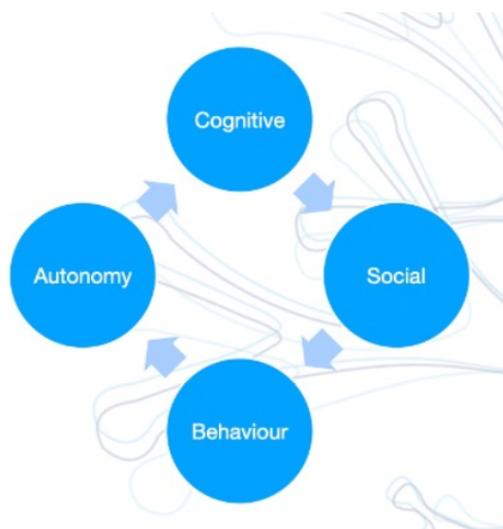
France takes the presidency of the EU Council

Since January, France has taken the presidency of the European Union Council for the next 6 months.

Olivier Véran, french health minister, reaffirmed France's unwavering commitment to **rare diseases**, and the French Presidency of the EU Council will make the fight against rare diseases a priority, with the stenghtening of the European Reference Networks.

Programme of the French Presidency

A word from our ePAGs



During the workshop in Rome, patient representatives presented their 3 priorities:

- Strengthen the Research and Innovation Capacity in the field of Burden of Disease (BoD) for an overall health objective.
- Multidisciplinary care needs to be more structured. More concrete actions for comorbidities are necessary especially for cognitive, behavioural, psychiatric and rehabilitation aspects.
- Grow and engage better with our Patient Community.

Our goal is to provide **BETTER QUALITY OF LIFE!**

International AHC awareness day

At the occasion of the International Day of Alternating Hemiplegia of Childhood (AHC), Torie Robinson from the [Epilepsy Sparks podcast](#) invited Rosaria Vavassori (founder of the [IAHCRC](#) and member of the EpiCARE ePAG) and Prof. Alexis Arzimanoglou (EpiCARE coordinator) to discuss this very rare genetic epilepsy!

Podcast on AHC

UNRAVEL project

Ring20 Research and Support UK CIO have launched a **new educational series UNRAVEL**: making genomic understanding of ring chromosome 20 syndrome possible, in collaboration with Illumina Inc.

A 2 phase project:

- Phase I aims to inform on what we do know and what we don't yet know about r(20) syndrome, from a genetic perspective.
- Phase II will be a feasibility study to try to find ways to make diagnosis easier, using whole genome sequencing techniques, to overcome the barriers to diagnosing ring chromosomes and reverse the diagnostic decline. If we can identify what's causing the ring to form, then we might even uncover clues to help researchers discover more effective treatment options in the future.

To find out more about this important project, check out the website:

<https://ring20researchsupport.co.uk/unravel/>.

EVENTS

EpiCARE Annual meeting is coming up!



The goal, as the ERNs are at the end of their first period, is to reflect on what was done, and prepare what can be planned in the next period!

It is also the perfect opportunity to get to know our new members, and give them a proper introduction to their new EpiCARE colleagues!

EpiCARE SCIENTIFIC PUBLICATIONS

- Lo Barco, T., De Gaetano, L., Santangelo, E., Bravi, T., Proietti, J., Cantalupo, G., Brambilla, I., & Darra, F. (2021). **SYNGAP1-related developmental and epileptic encephalopathy: The impact on daily life**. *Epilepsy & behavior : E&B*, 127, 108500. Advance online publication. <https://doi.org/10.1016/j.yebeh.2021.108500>
- Cohen, N. T., Cross, J. H., Arzimanoglou, A., Berkovic, S. F., Kerrigan, J. F., Miller, I. P., Webster, E., Soeby, L., Cukiert, A., Hesdorffer, D. K., Kroner, B. L., Saper, C. B., Schulze-Bonhage, A., Gaillard, W. D., & Hypothalamic Hamartoma Writing Group

(2021). Hypothalamic Hamartomas: Evolving Understanding and Management. *Neurology*, 97(18), 864–873. <https://doi.org/10.1212/WNL.0000000000012773>



You can consult recent publications on rare and complex epilepsies, epilepsy surgery and other topics on our [scientific publications webpage](#).

CASE DISCUSSIONS

EpiCARE Case Discussions are scheduled every 2nd, 3rd and 4th Wednesday of the month from 4:00pm to 5:30pm CET.

Both **surgical and non-surgical cases** are discussed by panels of experts, full or affiliated members of EpiCARE. [See the agenda on our website](#).

To receive the link to join the case discussions, you must register. Registration is only required once to be placed on the mailing list. [Follow this link to register](#).

WHAT IS NEW FOR YOU?

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.robort@epi-care.eu

Follow us on social media !



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