EpiCARE

OCTOBER 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

Overgrowth, epilepsy and genetics in FCD and hemimegalencephaly

November 3rd at 17:00 CET

Renzo Guerrini
&
William Dobyns

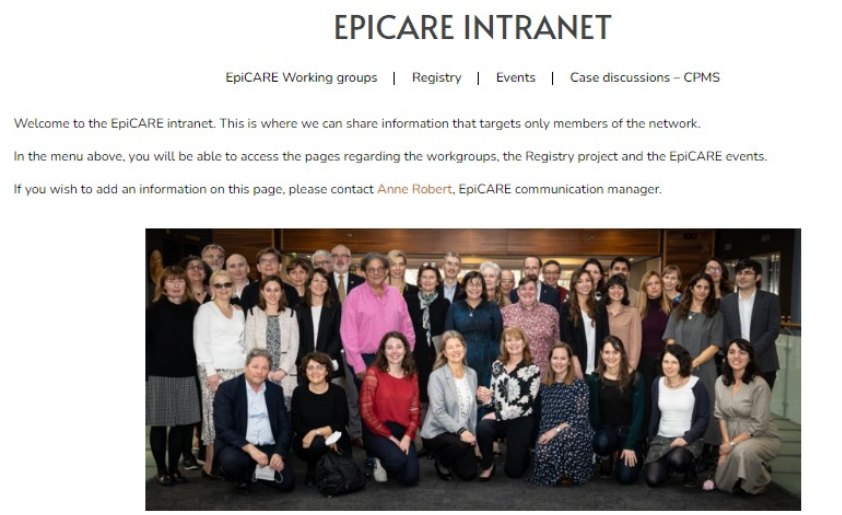
Register for this webinar

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?



The EpiCARE intranet is now accessible, for EpiCARE members only, on the main EpiCARE website (click on « intranet » on the top right), or with this link : EpiCARE intranet.

To get access, you first need to register (box on the left), mentioning your centre (if possible, please use the e-mail address given by your institution). This will send a request for approval to the administrators. Once approved, you will receive an e-mail (check in your spams) inviting you to create a password. You will then be able to login using the box on the right, and browse the intranet.

If you have any suggestion for more information to be on the intranet, or issues getting access, please do not hesitate to let us know !

New leaflet on Lennox-Gastaud syndrome !

Thanks to the work of Katia Santoro from LGS association Italy, Barbara Nicol for Association Epilepsy Spain, and Dr. Angel Aledo-Serrano (Ruber International Hospital, Madrid, Spain), we just published a new leafet on Lennox-Gastaut Syndrome.

As for the other leaflets, it contains 2 parts: one for healthcare professionnals, and one for the patient or their families and carers.

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

Solve-RD Webinar: The Treatabolome DB

In the last two years, the Treatabolome project, a Solve-RD initiative, promoted the collection of evidence about gene and variant-specific treatments for rare diseases.
*
The information, gathered by experts and published in systematic literature reviews, is now stored and accessible in the Treatabolome DB. Currently, the database

includes up to 180 treatments associated with more than 1000 distinct variants - mainly for neuromuscular disorders. Records are completed with clinical information by using standard vocabularies such as HPO, Orphanet, OMIM, Mesh and Chebi. The project is open to new data submissions and collaborations.

This webinar is especially relevant for people involved in rare disease diagnostics & care (clinicians, geneticists, genetic counsellors, etc.). It will:

- provide an overview on the Treatabolome DB
- explain how to use the information
- show how to find a treatment for a specific genetic disease
- show how new data is being included and how you can contribute

Date: Friday, 18 November 2022, 2pm CET
Speakers: Sergi Beltran, Alberto Corvo, Leslie Matalonga (all CNAG-CRG)
Registration link

EVENTS

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 !

REGISTER HERE - Watch out for the special rate for EpiCARE members!

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.

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:

- 29-31 Oct: 4th ILAE British Branch Epilepsy Neuroimaging Course. More info
- 14-17 Nov: All-ePAG meeting. Programme.
- 23 February - 25 June 2023: International Online Course on Pathogenesis of Epilepsy

EpiCARE SCIENTIFIC PUBLICATIONS

- Chávez López, E. K., Aparicio, J., Valera, C., Campistol Plana, J., Ramírez Camacho, A., Fons, C., & Arzimanoglou, A. (2022).
  Pre-surgical evaluation challenges and long-term outcome in children operated on for Low Grade Epilepsy Associated brain Tumors.
  European journal of paediatric neurology : EJPN : official journal of the European Paediatric Neurology Society, 41, 55–62. Advance online publication.
  Publication free for 50 days.

- Gregorčič, S., Hrovat, J., Bizjak, N., Rener Primec, Z., Hostnik, T., Stres, B., Perković Benedik, M., & Osredkar, D. (2022).
  Difficult to treat absence seizures in children: A single-center retrospective

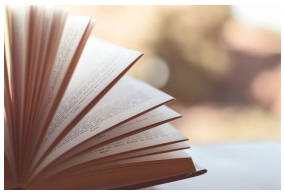
study. Frontiers in neurology, 13, 958369. Link.

- Neal, A., Bouet, R., Lagarde, S., Ostrowsky-Coste, K., Maillard, L., Kahane, P., Touraine, R., Catenoix, H., Montavont, A., Isnard, J., Arzimanoglou, A., Hermier, M., Guenot, M., Bartolomei, F., Rheims, S., & Jung, J. (2022). Epileptic spasms are associated with increased stereo-electroencephalography derived functional connectivity in tuberous sclerosis complex. Epilepsia, 63(9), 2359–2370. Link

- Cross, J. H., Reilly, C., Gutierrez Delicado, E., Smith, M. L., & Malmgren, K. (2022). Epilepsy surgery for children and adolescents: evidence-based but underused. The Lancet. Child & adolescent health, 6(7), 484–494. Link.

- Blümcke, I., Biesel, E., Bedenlier, S., Händel, M., Wilmshurst, J., Mehndiratta, M. M., Yacubian, E. M., Cendes, F., Arzimanoglou, A., Beniczky, S., Wolf, P., Giavasi, C., Baxendale, S., Shisler, P., & Wiebe, S. (2022). A structured, blended learning program towards proficiency in epileptology: the launch of the ILAE Academy Level 2 Program. A structured, blended learning program towards proficiency in epileptology: the launch of the ILAE Academy Level 2 Program. Epileptic disorders : international epilepsy journal with videotape, 24(5), 737–750. Link.

- Jehi, L., Jette, N., Kwon, C. S., Josephson, C. B., Burneo, J. G., Cendes, F., Sperling, M. R., Baxendale, S., Busch, R. M., Triki, C. C., Cross, J. H., Ekstein, D., Englot, D. J., Luan, G., Palmini, A., Rios, L., Wang, X., Roessler, K., Rydenhag, B., Ramantani, G., … Wiebe, S. (2022). Timing of referral to evaluate for epilepsy surgery: Expert Consensus Recommendations from the Surgical Therapies Commission of the International League Against Epilepsy. Epilepsia, 63(10), 2491–2506. 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

SUDEP awareness day
On 19th of October, we talked about the largest cause of death in people with epilepsy, and spread the word through increased awareness and taking actions to reduce SUDEP risks. Sudden unexpected death in epilepsy is by far the most severe complication of epilepsy. The knowledge about SUDEP is unfortunately still scarce, and it is a topic that is rarely mentioned in the conversations between patients and physicians. It is true that many patients are frighten by it, but although it is scary and undesired, it is present, and for some a harsh reality. While research in this area is ongoing, we cannot stop to ask ourselves is there a way to prevent it. But if we don't have open conversations with our physicians, how will we know what are the risk factors, how will we know when to act, how will we differ life-threating seizures? Many families wish that they have known that sooner, before the went through an unimaginable and heart-breaking loss. Together we need to change this! Individual counselling and conversations with psychological support can help us understand it more, and allow us to use current knowledge to do everything we can to reduce the risks.

10th Anniversary AHC Meeting and
ATP1A3 in Disease Symposium
(Edinburgh, 19 – 21 October 2022)

Alternating Hemiplegia of Childhood (AHC) is a very rare and complex neurological disease included in EpiCARE-ERN. In 2012 the ATP1A3 gene was discovered as primary cause of AHC. Since then, the annual edition of the international "ATP1A3 in Disease" Symposium is organized each year in a different country, to gather researchers, clinicians, families and all stakeholders involved in the study, care, management, and life with AHC, with the aim to get an update about the progress of research on the disease, to share ideas for new studies, to create new collaborations

and launch new projects and common actions at the international level. This year, on the special occasion of the 10th anniversary from the discovery gene, an extended three-days meeting was organized in Edinburgh, 19-21 October thanks to a project presented at the EJP-RD networking call that was approved for funding last march. Our ePAG, Rosaria Vavassori, has been a member of the Organizing Committee, also as EpiCARE Patient Advocate (EPAG), and partner for the EJP-RD project, which was coordinated by the English family association AHC-UK. The great thing about this symposium is that it allowed many other topics, included in the programme of the Symposium by the patient representatives, about the burden of the disease on the everyday life of AHC patients and their families, and about the best strategies to alleviate it. One of the speakers was Isabella Brambilla, ePAG coordinator, and Rosaria presented 2 posters.

Hope for Hypothalamic Hamartomas
On 30th of September, Hope for HH-UK was honoured to be one of two patient organisations invited to attend and speak at the European Leksell Gamma Knife Society Meeting 2022 where participants also celebrated 30 years of Gamma Knife Surgery at the Timone Hospital in Marseille. Opening the conference, Prof. Jean-Marie Régis recognised the critical role that patient advocacy organisations play in supporting patients, funding research and driving doctors to do better. Emma Nott, a trustee of Hope for HH-UK, later addressed the conference on behalf of the patient community, ensuring the patient voice was central to discussions.
On 23rd of October NHS England announced it would be funding a "pioneering laser bean treatment for epilepsy patients" that "will give those with epilepsy a real chance to live a normal life". Hope for HH was instrumental in securing NHS funding for this cutting edge surgical technology, which the charity has supported since it was first trialled on hypothalamic hamartoma patients in Texas from 2012. When the success of this pilot series became apparent, Hope for HH-UK lobbied for its use in the UK and in Europe. In 2018 the Ronson Family Foundation secured funding for the equipment to be installed at Great Ormond Street Hospital, London and also funded the pilot UK series on HH patients. At the same time, a Hope for HH-UK trustee joined the National Policy Group for NHS funding of the laser; finally, this work has resulted in the treatment being made available in the UK - not just for HH patients, but for patients of other focal epilepsies that are not controlled through medication.

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 !

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