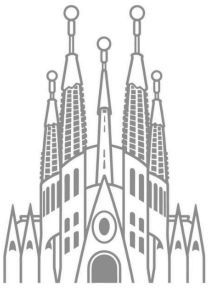
May 2024 NEWSLETTER

If you want to be informed about our next events, educational and research activities and calls, but also news from the coordination team, our different members and our ePAG community...don't miss this **Newsletter**!

Feel free if you want to **forward** this newsletter... and here is the link to sign up and receive it every month!

In 2018, the European Commission developed this wonderful video '*How the EU connected experts to treat epilepsy*' as an example of the missions of the ERNs. On the eve of the 2024 EpiCARE General Assembly, we would like to share with you again this important message.

2024 EpiCARE Annual Meeting (Barcelona)



EpiCARE General Assembly
June 2024, Barcelona

EpiCARE

The General Assembly is about to arrive! We are looking forward to meeting you in Barcelona, Spain, on June 17th. For now, it is a great pleasure to share with you the **programme** of the meetings we will enjoy (attached in the mail).

Members of EpiCARE accredited centers can participate online to any of the sessions, but a registration is nedded using **this link**.

NEXT WEBINAR

Thursday May 27th - 17h CET
Mimics of autoimmune encephalitis

Presented by: Sarosh Irani and Maarten Titualer
Chair: Masa Malenica

Register here

Our webinars take place **once a month**, and the replays are always available on our website. You can check the programme of the upcoming webinars and register to the mailing on the EpiCARE webpage:

Webinars webpage

New Gene Therapy Webinar Series

The webinar series on Gene Therapy is co-organized by ERN-RND, EURO-NMD, ERN EpiCARE and the European Academy of Neurology (EAN). Together we'll delve into the latest advancements and breakthroughs in this interesting field!

- **06.06.2024**, 4 pm CEST | *'Health technology assessment of genetic therapies*' by Oriana Ciani. Registration here.
- **13.06.2024**, 4 pm CEST | '*Genetic Therapies and Therapy Developments for ALS*'by Juan Francisco Vázquez Costa, University of Valencia, Spain. Registration here.
- **19.06.2024**, 4 pm CEST | 'Safety issues in gene therapies and how to address them' by Francesco Muntoni. Registration here.
- **27.06.2024**, 4 pm CEST | '*Genetic Therapies and Therapy Developments for SMA*'by Jan Kirschner, Medical Center – University of Freiburg, Germany. Registration here.
- **02.07.2024**, 4 pm CEST | '*State of the Art of Clinical Stage Gene Therapies for Leukodystrophies*' by Caroline Sevin, Kremlin Bicêtre Hospital, France. Registration here.

- **23.07.2024**, 4 pm CEST | '*Genetic Therapies and Therapy Developments for Rare Movement Disorders (HD, SCA)*' by Willeke van Roon-Mom, Leiden University Medical Center, the Netherlands. Registration here.

Gene Therapy Webinar Series

European Reference Network | Neuromuscular Diseases (ERN EURO-NMD) | EpiCARE

ean european academy of neurology | European Reference Network | Neurological Diseases (ERN-RND)

LATEST NEWS

15/5: Tuberous Sclerosis Complex (TSC) Global Awareness Day - Alexis Arzimanoglou interviews

Alexis Arzimanoglou, coordinator of EpiCARE and Director of the Epilepsy Program at the Hospital Sant Joan de Déu Barcelona, has been interviewed by the Spanish newspaper 20minutos and by ¡Hola! magazine to talk about Tuberous Sclerosis Complex.
The reason for these interviews was the **Tuberous Sclerosis Complex (TSC) Global Awareness Day,** celebrated on 15 May. Take 5 minutes to read it and learn more about this rare diseas.


Alexis Arzimanoglou, neuropediatra: "La discapacidad intelectual está presente en la mitad de los pacientes de esclerosis tuberosa"

MERCHE BORJA | NOTICIA | 15.05.2024 - 07.50 H

- El 15 de mayo es el día internacional de esta enfermedad que afecta a unas 4.000 personas en España.
- Antonio Gil-Nagel, referente mundial en epilepsia: "El diagnóstico precoz es más relevante de lo que se creía".

Alexis Arzimanoglou, Coordinador de la red Europea de referencia para epilepsias raras y complejas, ERN EpiCARE. / Cedida

Distintas **mutaciones genéticas** -ya sean espontáneas o heredadas- están detrás de la **esclerosis tuberosa, o Complejo de Esclerosis Tuberosa (CET)**, una enfermedad poco frecuente (afecta a 1/10.000 nacimientos) que puede causar **distintos grados de discapacidad**, dependiendo de la afectación. Entre los síntomas más comunes, el crecimiento de tumores

DÍA MUNDIAL DE LA ESCLEROSIS TUBEROSA

Álvaro Villanueva, padre de un niño con esclerosis tuberosa: 'Ha sido una lucha constante'

Esta enfermedad se manifiesta de formas muy diversas en cada paciente, desde no presentar síntomas a manifestar otros muy graves, como retraso intelectual o problemas cardíacos

Big data and collaborative research: The Human Intracerebral EEG Platform - Pr. Philippe Ryvlin

Most centers have limited data from intracerebral EEGs each year. Making progress in understanding human brain function using these data requires collaboration. Enter the Human Intracerebral EEG Platform (HIP), a cloud-based, collaborative environment that encourages centers to share data and conduct research with state-of-the-art methodologies and software. Dr. Maryam Nouri interviews Dr. Philippe Ryvlin.

MOOC: Free access until June 3!

Thrilled to announce the launch of a comprehensive **MOOC Health Data Ethics & Regulatory Frameworks in Rare Disease Research**! Developed by Foundation For Rare Diseases, EURORDIS, EpiCARE and Gianni Benzi Foundation, our MOOC promises valuable insights and knowledge expansion. From

May 6th to June 28th, join it for an enriching learning experience with expert educators on hand to address your queries. The **access is free until June 3**!

Watch the trailer here!

Join the course

New Calls for Collaborative Genetic Research!

Please find the **new calls** published on the EpiCARE website to encourage participation in **collaborative genetic research projects**. Find out more about the collaborative research calls, on this webpage.
If you have any question, feel free to contact Sébile Tchaicha, EpiCARE Research projects manager.

EpiCARE GOP PLATFORM

EVENTS

JUNE

EAN (European Academy of Neurology). Helsinki, Finland. Date: 29 - 2

The 10th **Congress of the European Academy of Neurology** will take place in Helsinki and online format. The main theme for the congress is '**Neuromodulation: advances and opportunities in neurological diseases**' which will be the focus of several sessions. The congress programme will offer symposia, workshops, teaching sessions, and much more.

JULY

"Continuare a curare". Pavia, Italy. Date: 4- 5

"Continuare a curare" offers an **Interdisciplinary working models to support the transition to adulthood in neurological and psychiatric disorders**, organized by SINPA (Italian Society of Neuropsychiatry Childhood and Adolescence). The course is designed for medical specialists in Neurology, Child Neuropsychiatry, Paediatrics, Neurophysiopathology, Paediatrics, General Medicine and Psychiatry.

EpiCARE SCIENTIFIC PUBLICATIONS

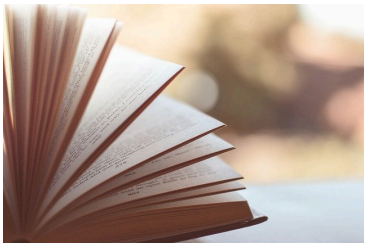
- Auvin S, Arzimanoglou A, Brambilla I, French J, Knupp KG, Lagae L, Perucca E, Trinka E, Dlugos D. **Call for the use of the ILAE terminology for seizures and epilepsies by health care professionals and regulatory agencies to benefit**

patients and caregivers. Epilepsia. 2024;65(2):283-286. doi: 10.1111/epi.17868. Open Access.

- Bozorg A, Beller C, Jensen L, Arzimanoglou A, Chiron C, Dlugos D, Gaitanis J, Wheless JW, McClung C. **Pitfalls of using video-EEG for a trial endpoint in children aged <4 years with focal seizures.** Ann Clin Transl Neurol. 2024;11(3):780-790. doi: 10.1002/acn3. Open Access.

- Geroldinger M, Verbeeck J, Hooker AC, et al. **Statistical recommendations for count, binary, and ordinal data in rare disease cross-over trials**. Orphanet J Rare Dis. 2023;18(1):391. doi:10.1186/s13023-023-02990-1. Open Access.

- Vignatelli L, Tontini V, Meletti S, et al. **Clinical practice guidelines on the management of status epilepticus in adults: A systematic review**. Epilepsia. Published online April 12, 2024. doi:10.1111/epi.17982. Open Access.



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.

NEWS FROM OTHER NEUROLOGY ERNS

Summer schools tailored for professionals in the field of neuromuscular diseases!

Dear EURO-NMD community,
we are excited to announce not just one, but two summer schools:

- *Neuromuscular translational summer school (6th edition)*
  - **Dates:** 9 – 12 July 2024
  - **Location:** Leiden University Medical Center, The Netherlands
- *Summer school on Multidisciplinary Management of Neuromuscular Diseases (1st edition)*
  - **Dates:** 12 – 14 September 2024
  - **Location:** Marseille, France

Whether you are an experienced professional or you are just starting in the field, these programs promise to enrich your knowledge and advance your skills in the dynamic realm of neuromuscular medicine!

A WORD FROM OUR ePAGs

New Patient Journey "Alternating Hemiplegia of Childhood"

We have a new document for the Disease Group Dystonias, NBIA and Paroxysmal Disorders: a patient journey on Alternating Hemiplegia of Childhood. The patient journey was developed together with the ERN epiCARE and the patient organization AHC18+. Find the patient journey as long and short version 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 info@epi-care.eu

Follow us on social media!

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