European Patient Advocacy Group

ePAG EpiCARE Newsletter
November 2024

It is our pleasure to announce that this year we will continue with our **newsletter** dedicated to patients' associations. It is our wish to **connect** and **engage more** with the wide community of rare and complex epilepsies and **provide better support** by disseminating relevant information.

If you wish to disseminate the information about your association, projects, activities and events you are planning, please contact: epag.epicare@gmail.com

AWARENESS DAYS

In November, we focus on raising awareness for three rare and complex neurological conditions: Lennox-Gastaut Syndrome (LGS) on November 1, PCDH19-Related Epilepsy on November 9, and Ohtahara Syndrome on November 15. These awareness days provide important opportunities to educate, advocate, and support individuals and families affected by these severe forms of epilepsy.

Lennox-Gastaut syndrome Awareness Day (November 1st)
Lennox-Gastaut syndrome (LGS) is a rare and severe form of epilepsy that typically begins in early childhood. It is characterized by multiple types of seizures, often resistant to treatment, along with cognitive impairments and developmental delays. LGS affects around 1-2% of children with epilepsy and poses significant challenges for families due to its complex and unpredictable nature. November 1st is a time to shine a light on the need for more effective treatments, greater support for caregivers, and continued research into the underlying causes of LGS.

PCDH19-Related Epilepsy Awareness Day (November 9th)
PCDH19-related epilepsy is a genetic condition caused by mutations in the PCDH19 gene, primarily affecting females. This form of epilepsy often manifests as seizure clusters that begin in early childhood and are associated with a spectrum of cognitive, behavioural, and psychiatric challenges. Awareness Day on November 9th highlights the urgent need for better diagnostic tools, personalized treatments, and deeper understanding of this rare condition. Advocating for research and community support remains vital in improving outcomes for individuals living with PCDH19-related epilepsy.

Ohtahara syndrome Awareness Day (November 15th)
Ohtahara syndrome, also known as Early Infantile Epileptic Encephalopathy (EIEE), is one of the most severe forms of epilepsy, typically presenting in the first few weeks of life. Characterized by frequent seizures and profound developmental delays, Ohtahara syndrome is often associated with underlying structural brain abnormalities or genetic mutations. Raising awareness on November 15th emphasizes the need for early diagnosis, access to specialized care, and advancements in research that could pave the way for improved treatments and support for affected families.

The Importance of Awareness and Advocacy
These November observances remind us of the urgent need to support those living with rare epilepsy syndromes and their families. By raising awareness and fostering dialogue within the medical and broader communities, we can drive progress in understanding, treatment, and care for these life-altering conditions.
Thank you for your continued commitment to these important causes. Thank you for supporting these awareness initiatives throughout November.

Patient Journey
We are happy to share with you that all published **Patient Journeys** are now available in **Portuguese**!
We'd like to thank João Ferreira for his time and effort dedicated in preparing the document translations! You can find all documents here.

EVENTS

Together for rare and complex epilepsies Follow up meeting

Next online meeting with the patient community for rare and complex epilepsies will be held on **December 12th at 6 pm CET**!
If your association would like to join the Alliance for complex and rare epilepsies please fill in the form available here.

We are also excited to announce the **hybrid meeting** for patient representatives of different rare and complex epilepsies! Workshops will be held **in Barcelona, Spain from May 9th to 10th 2025**.
To register please answer the following form.
If you wish to participate or need more information, please contact us.

For an EU commitment to tackling rare diseases

The European Economic and Social Committee (EESC) is holding a major conference entitled For an EU commitment to **tackling rare diseases** that will be held on **29th of November 2024 at 09:00 at Novotel Budapest City & Budapest Congress Centre** in **Hungary**. For more information, visit the event website.

This event will bring together a large number of stakeholders such as civil society organisations, patient associations, medical practitioners, researchers, hospital directors, health ministries and European institutions, and will ensure the continuity of the work and political commitment developed since 2004 by EU Member States, European institutions and civil society organisations.
This forthcoming conference will present the EESC's exploratory opinion drawn up at the request of the Hungarian Presidency of the Council of the EU on Leaving No One Behind: European Commitment to Tackling Rare Diseases and will disseminate the Committee's proposals, drawn from the conclusions of its opinions and conferences during the previous and current trio presidencies.
The EESC is organising this conference in order to deepen and gather the demands and recommendations of civil society organisations involved in the field of rare diseases with a view to drawing up the European Action Plan for Rare Diseases.
The event will be streamed in English and Hungarian.

For more information contact: RareDiseaseHU2024@eesc.europa.eu

European Reference Network evaluation: the way forward

This **webinar** will present the **European Reference Network evaluation results report** which will be published on 29 November 2024 here.
The report summarizes the results of a comprehensive evaluation of European Reference Networks (ERNs) and its members, **five years after their creation, focusing on their role in addressing complex and rare conditions**. **24 ERNs and 836 HCPs from 24 EU Member States and Norway** participated in the evaluation. The evaluation included self-evaluations, document reviews, ERN interviews, on-site audits of members and stakeholder interviews.
This report, drawing on a wide range of data, increases the understanding of the essential role of the ERN system in addressing rare diseases and conditions across Europe. It also presents relevant information on the structure, maturity, activity and impact of the ERN system, and identifies opportunities for improvement based on the findings of the stakeholder interviews and the evaluation to further enhance the evaluation process and ensure the continued sustainability of the ERN system.
The information and views set out in this report are those of the Independent Evaluation Body and do not necessarily reflect the official opinion of the Commission/Executive Agency.

Register to this webinar following this link.

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