European Patient Advocacy Group

ePAG EpiCARE Newsletter
December 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 December the focus is on raising awareness for several significant conditions and global observances: Infantile Epileptic Spasms Syndrome Awareness Week from December 1st to 7th, International Day of Persons with Disabilities on December 3rd, and Palister-Killian Syndrome Awareness Day on December 4th. These observances spotlight critical issues, offering opportunities to educate, advocate, and inspire action to support individuals and families living with disabilities and rare conditions.

Infantile Epileptic Spasms Syndrome Awareness Week (December 1st–7th)
Infantile epileptic spasms syndrome (IESS) is a rare but serious type of seizure disorder that typically occurs in the first year of life. Often characterized by sudden, repetitive movements and developmental regression, IESS can lead to long-term cognitive and physical challenges if not recognized and treated promptly. Awareness week aims to educate families, caregivers, and healthcare providers about the early warning signs—including subtle spasms or a sudden halt in developmental milestones—and the need for immediate medical intervention. Early diagnosis and treatment are crucial to improving outcomes for affected children.

International Day of Persons with Disabilities (December 3rd)
The International Day of Persons with Disabilities, celebrated every year on December 3rd, promotes understanding and inclusion of people with disabilities across all areas of life. This global observance serves as a powerful reminder to challenge stigma, celebrate achievements, and advocate for equal access to education, healthcare, and opportunities. The theme of this day varies each year, but the message remains the same: individuals with disabilities deserve dignity, respect, and inclusion as equal members of society. It is an opportunity to stand with our community and emphasize the need for ongoing support and accessibility in all aspects of daily life.

Pallister-Killian Syndrome Awareness Day (December 4th)
Pallister-Killian Syndrome (PKS) is a rare genetic condition caused by the presence of extra genetic material on chromosome 12. PKS can lead to developmental delays, intellectual disabilities, low muscle tone, seizures and distinctive facial features. This complex condition often requires multidisciplinary care, and affected families face significant challenges in securing resources and support. Awareness Day on December

4th helps shed light on PKS, fostering understanding, empathy, and advocacy for continued research and improved care.

Advocating Together for Awareness and Inclusion
December's awareness days highlight the interconnected themes of early diagnosis, support for individuals with rare conditions, and global efforts to foster inclusion and equality for people with disabilities. Together, by spreading awareness and sharing stories, we strengthen the community's voice and promote meaningful change for those impacted by infantile epileptic spasms syndrome, Pallister-Killian Syndrome, and disabilities worldwide.
Thank you for standing with us this December to support these important causes.

EVENTS

ePAG EpiCARE webinar: Building a Successful International Patient Network in Preparation for Future Scenarios

On December 19th at 5 pm CET ERN EpiCARE is organising a webinar dedicated to ePAGs. To register flow this link.

Together for rare and complex epilepsies Follow up meeting

Last meeting with patient organisations for rare and complex epilepsies this year was 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.

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.

In search of lost time: Challenging focal cortical dysplasias and autoimmune diseases with epilepsy

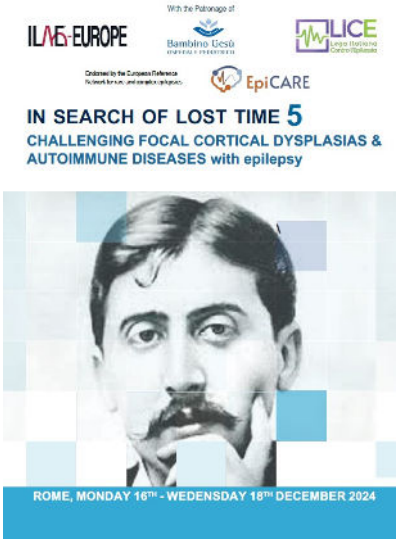
This year at the Rome workshop held from December 16th to 18th, our ePAGs held the session titled: ***Patient engagement in research and advocacy***.

The topics discussed, coupled with the enthusiastic commitment of patients to support every step of research and collaboration, highlighted a shared goal: achieving better cross-disciplinary care and an improved quality of life for individuals with rare and complex epilepsies.

One of the session's key highlights was the proposal to establish the Complex and Rare Epilepsy Alliance (CREA). This initiative received widespread enthusiasm from clinicians, researchers, and pharmaceutical companies, who recognized the potential for collaboration to overcome the fragmentation caused by the specific genetic definitions of epilepsy subtypes.

Despite the unique aspects of each condition, the session underscored that these rare and complex epilepsies share many common needs. CREA aims to work on providing innovative solutions for the patient community while advocating for greater recognition and socio-assistance support.

Special thanks go to Malgorzata Kosla, Irena Bibić, Carol-Anne Partridge, Sandra Silva Arrieta, and Isabella Brambilla, and all ePAGs within ERN EpiCARE, for their invaluable contributions.



Happy holiday from ePAG EpiCARE!

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