European Patient Advocacy Group

ePAG EpiCARE Newsletter
October 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

October is a critical month for raising awareness on multiple fronts within the rare disease and epilepsy communities. This month we recognize Rett Syndrome Awareness Month, GNAO1-Related Neurodevelopmental Disorder Awareness Day on October 1st, and SUDEP (Sudden Unexpected Death in Epilepsy) Awareness Day on October 16th. Each of these conditions presents unique challenges for affected individuals and families, and this awareness month serves as a time to amplify their voices and improve understanding and support within the broader community.

Rett Syndrome Awareness Month

Rett Syndrome is a rare, neurological disorder that primarily affects females and leads to severe impairments in speech, motor skills, and cognition. Occurring in approximately 1 in every 10,000-15,000 live female births, this condition requires intensive caregiving and specialized treatments, often involving a multidisciplinary team of healthcare providers. Throughout October, we focus on increasing awareness and supporting research into Rett Syndrome, with the hope that greater understanding can lead to improved therapies and, ultimately, a cure.

GNAO1-Related Neurodevelopmental Disorder Awareness Day (October 1st)

GNAO1-related disorders are a group of rare genetic conditions that stem from mutations in the GNAO1 gene, impacting neurodevelopment and often leading to significant motor challenges, developmental delays, and epilepsy. Due to the complexity of this disorder and its variability, individuals with GNAO1 mutations require highly personalized care and medical support. By raising awareness on October 1st, we aim to foster a deeper understanding of this condition and encourage continued research into treatment options for those affected.

SUDEP Awareness Day (October 16th)

Sudden Unexpected Death in Epilepsy (SUDEP) is a devastating phenomenon that affects some individuals with epilepsy, typically during or shortly after a seizure. While

SUDEP is relatively rare, it remains a leading cause of death among people with epilepsy. SUDEP Awareness Day on October 16th serves as a reminder of the importance of ongoing research into epilepsy, seizure management, and preventative strategies to reduce the risk of SUDEP. For families and loved ones of those affected by epilepsy, this day is an opportunity to honour those lost and to work toward safer outcomes for all individuals living with seizures.

Each of these awareness observances highlights the importance of continued advocacy, research, and community support for families affected by rare neurological conditions. By sharing these stories and raising awareness, we contribute to a future with better resources, treatments, and support networks for individuals with Rett Syndrome, GNAO1-related neurodevelopmental disorders, and epilepsy.
Thank you for supporting these awareness initiatives throughout October.

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 **November 14th at 6 pm CET**!

Save the date: Together for rare and complex epilepsies Hybrid meeting 2025!
The first hybrid meeting for patient representatives of different rare and complex epilepsies with workshops will be held in **Barcelona, Spain from May 9th to 10th 2025**.
More information will be available soon!

If you wish to participate or need more information, please contact:
epag.epicare@gmail.com

6th European GRIN Conference

It is with great pleasure that we inform you that the **on-line Registration for our 6th European GRIN conference is open**. To facilitate registration, we have created a website with all the information you will need to stay informed about the event. We will be updating the website with more information as we complete the program over the next few weeks.

We sincerely hope you can join us from **Friday November 8th until Sunday November 10th in Barcelona**. Please share this information with other family members and/or your local associations/family groups. We hope that many of you will be able to participate in the conference again this year in person; but for those who cannot travel to Barcelona, we are offering, once again, online registration for the Saturday and Sunday events.

The conference will start on Friday November 8th at 18h at the **Abba Garden Hotel** with the “Meet and Greet” social event and poster session, from 19-21:30h, in the *Cervantes* Room. During this social event we hope families, researchers and specialist will interact, grab a bite to eat and learn more about GRIN/GRIA research projects and the fantastic job some associations and family groups are doing in order to advance the knowledge about GRI disorders.

On Saturday November 9th we will have a full day of talks by 11 distinguished speakers working on GRIN and GRIA disorders. They will share with us their latest work and great advances in the field. This event will be held in the PCCB auditorium at the Sant Joan de Deu Hospital, from 9h-18h. This event will be followed by “Dinner with the Speaker” event at the Abba Garden Hotel.

On Sunday November 10th we will have a moderated Discussion about complex diagnosis and treatment of GRIN and GRIA symptoms. In this discussion round, we aim at presenting some of the challenges families encounter when trying to have their GRI-kids diagnosed and treated. We hope with this discussion to create awareness and engage the medical and research communities to help us find better treatment options for some of these complex problems.

We have an exciting program ahead and are sure you will enjoy it. Please join us in-person in Barcelona for the 6thedition of the European GRIN conference.

We are very much looking forward to seeing you in November.

The Board of GRIN Europe

GRIN EUROPE Care 4 GRIN

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*

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