European Patient Advocacy Group

ePAG EpiCARE Newsletter
July 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

GLUT1 Deficiency Syndrome Awareness Day

We are excited to share with you that July 10th marked GLUT1 Deficiency Awareness Day, a vital opportunity to shed light on this rare and often misunderstood condition. GLUT1 Deficiency Syndrome (GLUT1 DS) is a genetic disorder that impairs glucose transport across the blood-brain barrier, leading to an array of neurological symptoms.

This day is dedicated to increasing awareness, supporting affected families, and promoting advancements in research and treatment. By spreading knowledge about GLUT1 DS, we aim to foster a more inclusive and understanding environment for those impacted by the syndrome.

What is GLUT1 Deficiency Syndrome?

GLUT1 DS is caused by mutations in the SLC2A1 gene, which encodes the GLUT1 protein responsible for transporting glucose to the brain. Without adequate glucose, the brain cannot function properly, resulting in symptoms such as seizures, developmental delays, and movement disorders. Early diagnosis and intervention are crucial in managing the condition effectively.

Why Awareness Matters

Raising awareness about GLUT1 DS helps in several key ways:

- **Early Diagnosis**: Increased knowledge among healthcare professionals and the public can lead to earlier diagnosis and treatment, improving the quality of life for those affected.
- **Support and Community**: Awareness fosters a supportive community where families and individuals affected by GLUT1 DS can connect, share experiences, and find comfort.
- **Research and Funding**: Greater awareness can drive research initiatives and funding, leading to better treatments.

How You Can Help

- **Educate Yourself and Others**: Learn about GLUT1 DS and share information within your network.
- **Support Advocacy Groups**: Consider supporting organizations dedicated to GLUT1 DS research and patient support.
- **Participate in Events**: Engage in events and activities that raise awareness for GLUT1 DS.

We extend our heartfelt thanks to everyone who participated in GLUT1 Deficiency Awareness Day and those who continue to support this important cause. Together, we can make a difference in the lives of those affected by GLUT1 DS.

ePAG EpiCARE news

New Patient Journey

We are excited to announce the new Patient Journey for GRIN Related Disorders! We would like to take this opportunity to thank **GRIN Europe** and **Dr. Antonela Riva** for their time, effort and collaboration invested in producing this document! Patient Journey is available here!

Events

Different faces of rare and complex epilepsies

It is our pleasure to announce the second conference titled DIFFERENT FACES OF RARE AND COMPLEX EPILEPSIES, organised by **Dravet syndrome Croatia**, that will be held in **Split**, Croatia, at hotel Amphora, from T**hursday 17th to Saturday 19th of October 2024**. The conference aims to encourage knowledge sharing and productive discussions on rare and complex epilepsies, and it will be held in person and online. On 18th of October, panel discussions will be held for healthcare professionals in English, and on 19th of October panel discussion will be held in Croatian.
For full program and registration,
visit: https://dravetconference2024.conventuscredo.hr/en/.

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

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