



**European  
Patient  
Advocacy  
Group**

## **ePAG EpiCARE Newsletter August 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](mailto:epag.epicare@gmail.com)

### **EVENTS**

#### **Together for rare and complex epilepsies**

ePAG EpiCARE is happy to announce the follow up online meeting with representatives of patient associations for rare and complex epilepsies in Europe!

Online meeting will be held on **August 30<sup>th</sup> from 6 - 7.30 pm CET**.

If you missed the first online meeting on 31<sup>st</sup> of May, you can find the meeting summary [here](#).

If you wish to participate or need more information, please contact: [epag.epicare@gmail.com](mailto:epag.epicare@gmail.com)



#### **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 **Thursday 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 18<sup>th</sup> of October, panel discussions will be held for healthcare professionals in English, and on 19<sup>th</sup> of October panel discussion will be held in Croatian. For full program and registration, visit: <https://dravetconference2024.conventuscredo.hr/en/>.



## 6<sup>th</sup> 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 6th edition of the European GRIN conference.

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

*The Board of GRIN Europe*



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