



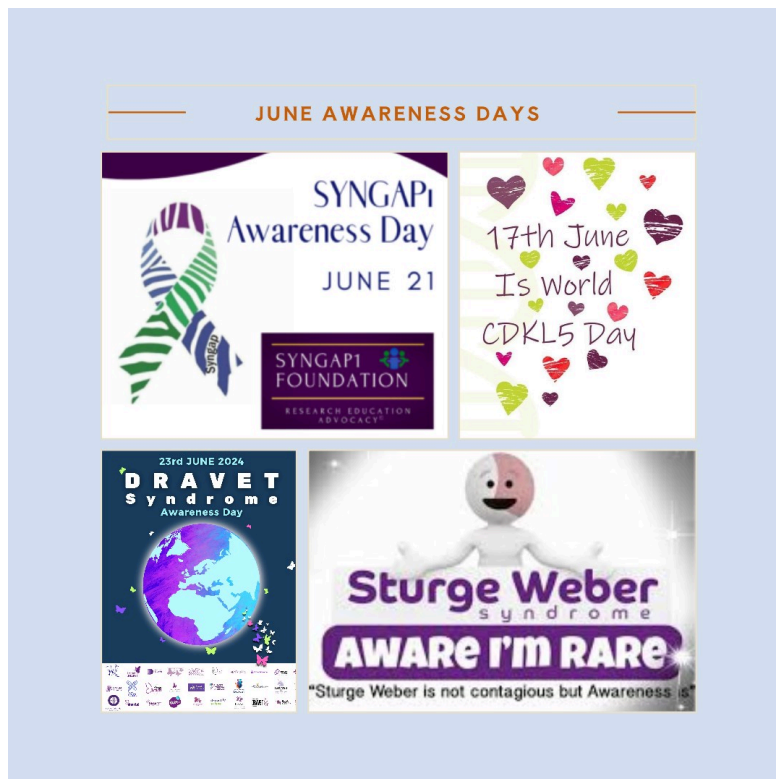
**European
Patient
Advocacy
Group**

ePAG EpiCARE Newsletter June 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



ePAG EpiCARE news

First online meeting with patient organisation for rare and complex epilepsies in Europe

"Together for rare and complex epilepsies" meeting was organised after receiving positive feedback from patient organisations. The survey received 89 responses, and all the participants expressed their interest in joining the first online meeting with the patient community, held on May 31st 2024. During the meeting 55 participants joined online. The speakers were prof. Alexis Arzimanoglou, Isabella Brambilla, Vedrana Bibić, Malgorzata Kosla, Irena Bibić, Matt Bolz Johnson and Kathy Redmond. The topics discussed were:

- ERN EpiCARE and ePAG activities
- Patient Journeys and leaflets
- Survey on rare and complex epilepsies plan
- Plan for face-to-face meeting with patient representatives in 2025.

We'd like to thank all the participants in their interest and active involvement, and would like to announce the follow up meeting planned for late August 2024! For more information please contact epag.epicare@gmail.com.



EpiCARE ERN Annual General Meeting

Members of ePAG EpiCARE: Isabella Brambilla, Irena Bibić, Carol-Anne Partridge, Maryse Arendt, Malgorzata Kosla, Zhana Chokheli, Bojana Mirosavljević, Vincent Chatain and Vedrana Bibić have met in person to join EpiCARE's AGM in Barcelona from 17th to 19th of June 2024.

We would like to thank the EpiCARE and ePAG team, and all the participants for great and productive 3 days through working group meetings, AGM and ePAG meeting, and for the opportunity to share the work of ePAG patient representatives and develop plans for further actions!



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 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 hybrid, both 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 more information, visit: <https://dravetconference2024.conventuscredo.hr/en/>.



Follow us on social media!



[Unsubscribe](#)

© 2021 EpiCARE All rights reserved.

You are receiving this email as you may work at one of the EpiCARE centres or you are taking part in one or more of EpiCARE expert groups or you may have attended one of our webinars.