



**European
Patient
Advocacy
Group**

ePAG EpiCARE Newsletter April 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

Autism Spectrum Disorder Awareness Day

As we observed Autism Spectrum Disorder Awareness Day on April 2nd, it is paramount to recognize the intricate connections between autism and rare and complex epilepsies. These intertwined conditions present unique challenges and needs for individuals, families, and caregivers navigating their journeys.

Autism Spectrum Disorder often emerges as one of the comorbidities in individuals with rare and complex epilepsies. This intersection underscores the importance of a comprehensive approach to care and support, considering the multifaceted nature of these conditions.

Understanding the specific needs of patients with both autism and rare epilepsies is essential for providing effective support. These individuals may require tailored interventions that address their unique challenges, ranging from communication difficulties to sensory sensitivities and complex medical needs.

As advocates and healthcare professionals, it is incumbent upon us to foster greater awareness and understanding of these intersecting conditions. By amplifying the voices of individuals with autism spectrum disorder or autistic traits and rare epilepsies and advocating for inclusive and supportive environments, we can make meaningful strides towards improving their quality of life.

Together, let's continue to raise awareness, promote acceptance, and advocate for the holistic care and empowerment of every individual affected by these conditions.

ePAG EpiCARE news

New Patient Journey

SYNGAP1 Patient Journey is now available [here](#)! We'd like to thank Luciana Degaetano for preparing the Patient Journey with prof. Lo Barco for the review, and SYNGAP España

Events



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

ePAG EpiCARE is happy to announce the 1st online meeting with representatives of patient associations for rare and complex epilepsies in Europe!

Online meeting will be held on May 31st from 6-8 pm CET.

Stay tuned as agenda and meeting links will be shared soon!

For more information, please contact: epag_epicare@gmail.com.



Syngap1 Family Race, Madrid, Spain

The first SYNGAP-1 solidarity race is a 5km and 10km race through the Montse del Pilar in Madrid. The donations collected from the race will go entirely to the research of this syndrome, which is a rare disease caused by a mutation in the Syngap1 gene.

For more information, here you have the <https://www.syngap1.es/>.

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/>.



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