European Patient Advocacy Group

ePAG EpiCARE Newsletter
May 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

Tuberous Sclerosis Complex Awareness Day

Yeasterday, May 15th, we came together to raise awareness about Tuberous Sclerosis Complex (TSC), a rare genetic disorder that affects approximately 1 in 6,000 people worldwide. TSC causes benign tumours to grow in vital organs, including the brain, heart, kidneys, lungs, and skin, leading to a wide range of health challenges.

***Understanding TSC**:*

Tuberous Sclerosis Complex is caused by mutations in the TSC1 or TSC2 genes. These mutations disrupt the regulation of cell growth and division, leading to the formation of noncancerous tumours. The symptoms of TSC can vary greatly, even among members of the same family, but common issues include seizures, developmental delays, autism spectrum disorder, skin abnormalities, and kidney/lung disease.

Living with TSC:

Living with TSC can be incredibly challenging, not only for those diagnosed but also for their families and caregivers. Medical management often involves a team of specialists, including neurologists, nephrologists, cardiologists, dermatologists, and others HCPs to address the multifaceted symptoms of the disorder. Early diagnosis and a comprehensive care plan are crucial for improving quality of life.

How You Can Help:

Awareness is the first step toward making a difference.

Educate: Learn about TSC and share information with your network to help increase understanding and empathy.

Advocate: Support policies, research and healthcare services for those affected by TSC.

Participate: Join local or virtual events to raise awareness about TSC research and support.

Let's stand together in solidarity with those living with TSC and their families. By raising awareness, advocating for research, and supporting those affected, we can make strides toward a future where TSC no longer limits lives.

ePAG EpiCARE news

AHC Patient Journey full text version

We are happy to share with you the efforts of AHC patient community, and their work in collaboration with ERN EpiCARE and ERN RND that resulted in publishing the full text Patient Journey, available here.

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**.
If you are a patient representative of an organisation for rare and complex epilepsy, register for the meeting here. Survey is open until May 27th.
For more information, please contact: 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 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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