European Patient Advocacy Group

# ePAG EpiCARE Newsletter
# October 2023

It is our pleasure to announce that this year we will start with a 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


### GNAO1 Awareness Day

On October 1st we marked the day to bring attention to GNAO1 Related Neurodevelopmental Disorders, a rare genetic condition with a unique and diverse range of phenotypes.
GNAO1 Related Neurodevelopmental Disorder is a genetic disorder caused by mutations in the GNAO1 gene, resulting in a spectrum of neurodevelopmental challenges. From movement disorders to seizures and varying intellectual abilities, the phenotypes can differ significantly from person to person.

Let's shed light on these differences and promote understanding:

Understanding the Spectrum: GNAO1 Related Neurodevelopmental Disorder showcases a wide spectrum of symptoms and abilities. It's essential to recognize and respect the individuality of each person affected by this disorder.
Educate and Advocate: Share information about GNAO1 related disorders, their various phenotypes, and how it impacts individuals and families. By spreading knowledge, we can reduce stigma and foster a more inclusive society.
Empower the Community: Encourage open conversations and support within the GNAO1 community and beyond. Embrace diversity and celebrate the unique strengths and abilities of every individual, regardless of their challenges.
Research and Progress: Advocate for continued research into GNAO1 related disorders. Increased understanding of this disorder can lead to improved treatments, therapies, and ultimately, a better quality of life for those affected.
Together, let's work towards a world where individuals with GNAO1 Related Neurodevelopmental Disorder are seen, understood, and celebrated for their distinctive qualities.

### Rett syndrome Awareness month

October is Rett Syndrome Awareness Month! Let's shine a light on this rare and often misunderstood disorder to make a difference.
Rett Syndrome is a neurological disorder that primarily affects girls, causing severe physical and cognitive impairments. It's time to come together, raise awareness, and support those living with Rett Syndrome and their families.
Here's how you can help:

- Learn About Rett Syndrome: Take some time this month to educate yourself and others about Rett Syndrome. Understanding is the first step toward empathy and change.
- Share Information: Share facts, stories, and resources about Rett Syndrome including the EpiCARE leaflet on Rett syndrome.
- Support Research and Families
- Advocate for Inclusivity: Raise your voice for inclusivity and accessibility for individuals with Rett Syndrome. Advocate for their rights and opportunities in your community.

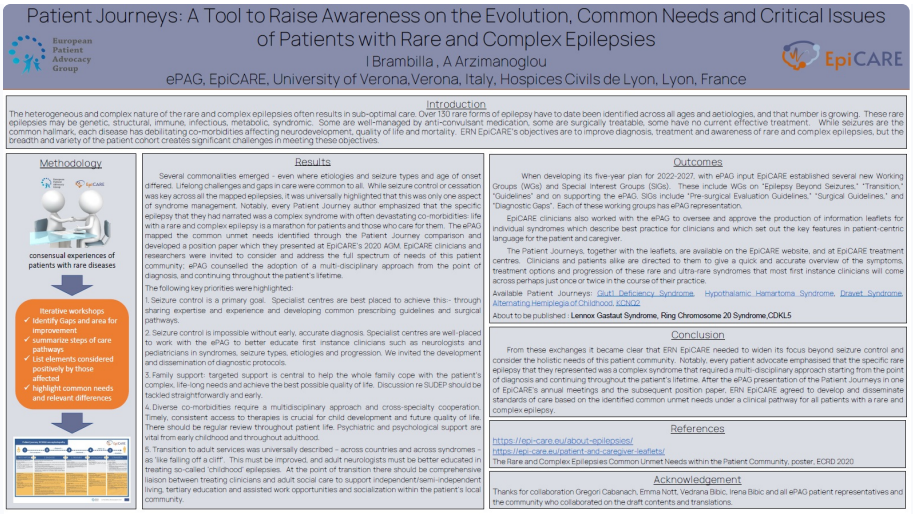
Together, let's create a world where individuals with Rett Syndrome are understood, supported, and empowered to reach their full potential.

### SUDEP Awareness Day

October 18th is SUDEP Awareness Day! Let's spread awareness and support for those impacted by Sudden Unexpected Death in Epilepsy (SUDEP).
SUDEP is a topic that affects many individuals and their families. Knowledge is power, and understanding the risks associated with epilepsy can make a significant difference. Let's unite to raise awareness, educate, and advocate for better care and research to minimize the occurrence of SUDEP.
Here are a few ways you can participate and make a difference:
Educate Yourself and Others: Learn about SUDEP and its risk factors. Share this knowledge with your loved ones to ensure a safer environment for those with epilepsy, share stories and experiences and support epilepsy research!
Together, let's work towards a world where everyone impacted by epilepsy can live without fear, and where research and understanding reduce the risks associated with this condition.

## ePAGs EpiCARE news

### IEC 2023 ePAG poster




Poster presented at IEC 2023 in Dublin by ePAGs titled [Patient Journeys: A Tool to Raise Awareness on the Evolution, Common Needs and Critical Issues of Patients with Rare and Complex Epilepsies is now available on the EpiCARE website.]

## New leaflets and Patient Journeys

Translations are progressing and we are regularly uploading translations in different languages for different rare and complex epilepsies! Currently there are over 30 translation in 11 languages!

If you wish to disseminate information about your disease, share the knowledge and raise awareness in your own national language, contact us at: epag.epicare@gmail.com

# Upcoming events

### Dravet Syndrome UK Parent/Carer Conference

Friday 17th November

In-person at the Leonardo Royal Hotel, London City OR live-stream online

Dravet Syndrome is a complex epilepsy. As well as seizures, those affected have learning disability (severe to profound in over 75%), autism, challenging behaviour and difficulties with speech, mobility, feeding and sleeping.

The DSUK Parent/Carer Conference is a unique opportunity for parent/carers, who require practical support and information for all aspects of living with this devastating condition to meet with others who are going through the exact same experiences. It also offers a unique opportunity to meet and to hear directly from expert guest speakers from the UK and around the world. From learning about family rights, to discovering insights about the latest research and treatments; from asking Dravet experts your burning questions to sharing experiences with other Dravet families - our conference provides a friendly environment for furthering knowledge and understanding about living with Dravet Syndrome.

You can view the full agenda and register to attend by visiting the Dravet website.

### Dravet Syndrome UK Professionals Conference

Saturday 18th November

In-person at the Leonardo Royal Hotel, London City OR live-stream online

The medical and scientific understanding of Dravet Syndrome has increased significantly during recent years. We've entered an incredibly exciting and hopeful time for the future of Dravet Syndrome, with developments in gene therapy and other treatments that seek to address not only the symptoms of the condition but also its underlying causes.

We're pleased to invite you to the DSUK Conference Professionals Day - the only scientific meeting in the UK that is dedicated to furthering knowledge about Dravet Syndrome. The conference, chaired by Professor Helen Cross OBE, delivers a packed agenda of leading voices in Dravet Syndrome to enable discussion of the latest updates, news and medical research.

The DSUK Conference Professional Day is CPD accredited by the RCP and the RCPCH.

Further information and registrations.

### LES RENCONTRES NATIONALES DE L'ALLIANCE SYNDROME DE DRAVET 2023: JOURNÉE FAMILIALE – Family meeting

The French Dravet association (Alliance Syndrome de Dravet, 'ASD') is organizing annual family meeting! It will take place in Paris, on 25th and 26th of November 2023, and will be held in French. So, if you are fluent in French or know somebody who is, please join and share the information!
For full program and registration visit the website

### Rome workshop In search of lost time: Epilepsy care challenges from neonates to adults

Workshop In search of lost time will be held in Rome, from December 13th to 15th. During the workshop, our ePAGs will gather for a session: Epileptic Seizures in neurological disorders: the role of Patient Advocates.
For more information and registration click here.

### Save the date for European Dravet Syndrome Conference 2024

Fundación Síndrome de Dravet is organising a Dravet syndrome conference in 2024. Save 14th and 15th of March 2024 in your calendars and join the conference in Madrid.
For preliminary program and registration, click here.

## Meet the patients' associations

Association d'Aide aux Personnes Epileptiques

A.A.P.E - Association d'Aide aux Personnes Epileptiques, is a not-for-profit voluntary association founded in 1997 by people with epilepsy and parents of children with epilepsy, whose mission is to provide information about epilepsy and to defend the interests and rights of people with epilepsy.

It is the only patient organisation for epilepsy in Luxembourg. Recently we have been approached by families with different rare epilepsies, this showed the importance to join EPAG and collaborate in the EpiCARE Working groups.
As we are living in a small country with no excellency centre in epilepsy, we are aware that we need international connections to share experiences and information.
Our main aims and objectives are:
- to bring together people directly or indirectly affected by epilepsy
- to provide people with epilepsy and their families with moral, medical, psycho-educational and social information likely to help them
- to strengthen bonds of friendship and mutual support between its members
- to work together to find solutions to the complex problems posed by epilepsy
- to provide information and promote dialogue with all professional groups affected by epilepsy
- to help inform the public in order to combat the prejudices associated with epilepsy

An important project started when we were recognized as facilitators and trainers on epilepsy for teachers.
Our seminars are building or increasing the knowledge on different forms of epilepsy and their manifestations, as well as the side effects of epilepsy treatment on school performance. The participants become competent in their reaction to an epileptic seizure. Teachers and pedagogic assistants will be able to deal with a child with epilepsy in class, during sports and school trips and adapt the environment as well as destigmatizing epilepsy for other pupils.

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Dravet syndrome Hrvatska

Dravet Syndrome Croatia is a non-profit association founded in 2014 that gathers patients and families affected by not only Dravet syndrome but also other rare and complex epilepsies.

Main objectives are to improve the quality of life of patients and families living with rare and complex epilepsies through raising awareness, education of families and healthcare professionals, and improving the availability of drugs in Croatia.
Dravet syndrome Croatia has many active programs of which highlighted are EpiPrehrana, a program for Ketogenic Dietary Treatment, Advent Dravet, a one day education for families and healthcare professionals, and Koracima Nade, education and 2-day family gathering.

Webpages: https://dravet-sindrom-hrvatska.hr/, https://epiprehrana.com/
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Telephone: +385 95 908 0428
Facebook
Instagram
YouTube

CDKL5 UK

CDKL5 UK is a non-profit charity that provides support to families, funds research and provides patient advocacy through collaborative working with clinical networks, and industry.
Currently they are providing patient expertise and advocacy as a stakeholder in a NICE appraisal of Ganaxolone, an anti-seizure medication which has shown efficacy in CDKL5 deficiency disorder and the only approved medication specifically for CDKL5. CDKL5 UK has also held a number of international meetings for the CDKL5 community. We work closely with the clinical community in the UK and Europe, and with pharma, ensuring that our families are able to access new technologies as they become available. We are co-authors on a number of papers which look at the lived experience of patients living with CDKL5 and their families. We are reworking our mission and will be re-launching our new priorities soon, which will we hope will include mental health support for families who are living with CDKL5.

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