ePAG EpiCARE Newsletter
November 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

Lennox Gastaut syndrome Awareness Day

Lennox-Gastaut Syndrome (LGS) Awareness Day is an annual observance dedicated to raising awareness about Lennox-Gastaut Syndrome, a rare and severe form of epilepsy. November 1st serves as an opportunity to educate people about the condition, provide support to individuals living with LGS, and advocate for improved research and treatment options. Here's some key information about Lennox-Gastaut Syndrome Awareness Day:

Purpose: The primary purpose of this day is to increase understanding and awareness of Lennox-Gastaut Syndrome and the challenges faced by those living with the condition. It's an occasion to promote empathy, support, and inclusion for LGS warriors and their families.

Lennox-Gastaut Syndrome: LGS is a rare and severe type of epilepsy characterized by multiple seizure types, cognitive impairments, and developmental delays. It often begins in childhood and can have a profound impact on an individual's life, as well as their families and caregivers.

Advocacy and Research: The day is also an occasion to advocate for increased research and treatment options for LGS. Ongoing research is crucial to finding better

ways to manage and treat this complex condition.

Raising awareness about Lennox-Gastaut Syndrome is essential to creating a more informed and empathetic society and supporting those living with this challenging condition. To learn more, check out this LGS leaflet.

PCDH19 related epilepsy Awareness Day

On November 9th we marked PCDH19-Related Epilepsy Awareness Day!
We came together to raise awareness about PCDH19-Related Epilepsy, a rare and complex form of epilepsy that predominantly affects young girls. This was a day to show our support and understanding for those affected by this condition.
PCDH19-Related Epilepsy is a genetic epilepsy syndrome linked to mutations in the PCDH19 gene. It primarily strikes girls and brings with it a unique set of challenges. Seizures, developmental delays, and intellectual disabilities are common features.
For PCDH19 warriors and their families, life is a journey filled with courage and resilience. Daily life can be marked by unpredictability as seizures may strike at any moment. This makes simple activities like school, play, and sleep a constant challenge. Coping with the emotional and physical toll of these seizures can be overwhelming, but these incredible individuals and their families continue to face each day with determination and hope.
Help us raise awareness by:

- Education about PCDH19-Related Epilepsy.
- Offering support, empathy, and kindness to those living with this condition.
- Join us in raising awareness and providing strength to those on this challenging journey. Together, we can make a positive impact.

Ohtahara syndrome Awareness Day

November 15th was dedicated for Ohtahara Syndrome Awareness Day!
Together we shed light on Ohtahara Syndrome, a rare and devastating form of epilepsy that affects infants in their earliest months of life. This date we emphasize spreading awareness and offering support to those battling this challenging condition.
Ohtahara Syndrome is a severe and rare form of epilepsy that typically begins in the first few months of a baby's life. It's characterized by frequent and often intractable seizures, causing developmental delays and challenges for both the child and their family.
Ohtahara Syndrome presents a profound impact on daily life for affected families. The constant worry and care required can be emotionally and physically draining. The journey is filled with hospital visits, therapy sessions, and a deep desire to provide the best possible life for their child.
How can you help?

- Share this post to raise awareness and educate your network.
- Learn more about Ohtahara Syndrome and share your knowledge.
- Extend your support and empathy to those affected by this condition.

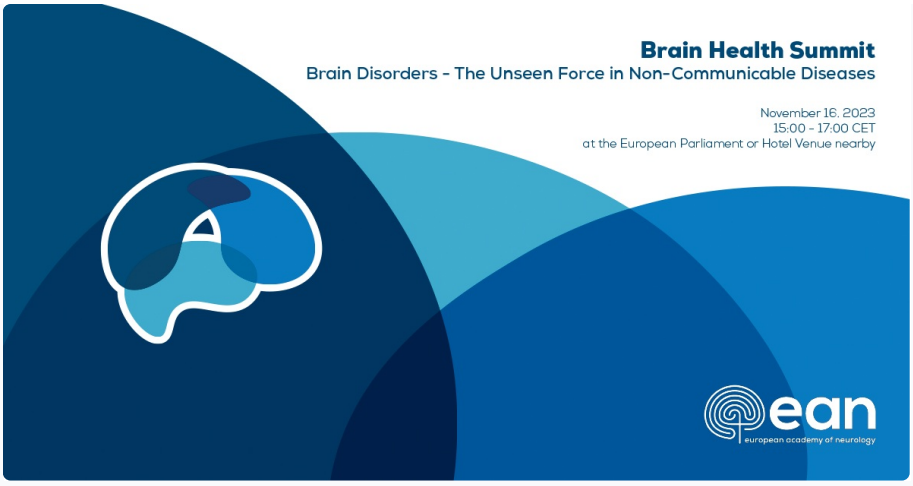
ePAGs EpiCARE news

New leaflet translations

Translations are progressing and we are regularly uploading translations in different languages for different rare and complex epilepsies! Currently there are over 30 translations in 12 languages! Newly added is Ring 20 leaflet in Lithuanian!
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

Brain Health Summit - November 16th



We are glad to share that Isabella Brambilla, ePAG Chair, has been invited to participated in this year's Brain Health Summit, to speak in the Patient Discussion 'Patient Perspective: the potential for accessible, quality neurological care to reduce the burden of NCDs' .

You can register to follow the event virtually here.

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 visit: https://rareepilepsyworkshops.net/

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.

5th European GRIN Conference – follow up

The 5th European GRIN conference was held in Barcelona on October 7th and 8th with over 150 participants online and in person. We want to extend our big Thank You! to all the families, researchers, doctors, and GRIN association ambassadors and other coordinators who attended this exciting event.
It was a pleasure to see all the positive engagement from all parties. This was an important gathering for our GRIN community, with a global representation of over 15 different countries.
Such a great arena to engage for more future GRIN related research, knowledge, and awareness.

Meet the patients' associations

CASK Coalition

The CASK Coalition is a group of like-minded collaborative CASK research non-profits. The aim of the CASK Coalition is to harmonize and mobilize the full force of CASK foundations toward advancing treatments and a cure for CASK disorders. Members of the coalition use their skills to assist one another, exchange ideas, share contacts and work together with the common aim of finding a treatment or cure for CASK disorders. We urge non-profits to prioritise collaboration over competition, for the sake of those suffering.

Why a coalition?

With roughly 300 confirmed diagnoses, the CASK community is small and dispersed across different countries. United by a Facebook group that offers a critical platform for sharing information and providing support across CASK families, the community is currently represented by multiple foundations spanning the globe. Given the size of the community and the enormous obstacles to advancing treatments and a cure for rare diseases, the CASK community would benefit from collaboration in defining a community-wide research Road Map, promoting unified data collection, and undertaking fundraising and outreach collectively.

- MISSION: To facilitate collaboration between CASK non-profits and researchers in order to accelerate the path to a treatment or cure for CASK disorders. To enable one louder voice of advocacy rather than many small voices.
- VISION: A world where a treatment or a cure for CASK disorders is found quickly as a result of collaboration.
- VALUES: Committed – Collaborative – Expeditious

We work closely with the clinical and research community in Europe and at international level, ensuring that our rare disease community is able to access new technologies as they become available. CASK aims to follow in the footsteps of two more common X-linked genetic disorders: MECP2 and Rett syndrome. We are currently funding a research project, we called CURE CASK, which is a second-generation gene therapy based on Xi reactivation. More information to come soon!

Cask Coalition is also in contact with research teams looking for drugs that may prevent cerebellar degeneration due to CASK loss and or generally may improve the quality of life of children suffering from the Cask Gene disorder.

Below the members of the CASK Coalition:

ANGELINA CASK NEUROLOGICAL RESEARCH FOUNDATION (AUSTRALIA) AND (USA)
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ASSOCIATION ENFANTS CASK FRANCE
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Email: associationenfantscaskfrance@gmail.com

Les petits Mecp2

The French-speaking association “Les petits Mecp2” is dedicated to families affected by MECP2 gene duplication syndrome, a rare, progressive and serious genetic anomaly.

Association les petits MecP2
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lespetitsmecp2.org

Our missions aim to support families, inform about scientific advances, finance research projects and support the implementation of upcoming clinical trials in FRANCE.

Founded in 2016, at the initiative of families whose children are affected by MECP2 gene duplication syndrome on XQ28, the Les Petits Mecp2 association was born following a medical publication from the United States, demonstrating the character reversible of this genetic anomaly.
It is with the desire to support families and develop medical research on this anomaly in the hope of improving the living conditions of these children that the association initiated the project to support research.
The energy of the members makes it possible to raise three important missions within the association:
Supporting families: by sharing experiences with families awaiting diagnosis or newly diagnosed, to improve the lives of children (thanks to medical and therapeutic monitoring, exchanges between families, testimonies from loved ones and useful documents and links) .
Inform about research: by following the progress of research projects, by informing families about scientific progress and advances (notably on current projects, registers, expert webinars and publications).
Raise awareness and finance projects: by identifying viable projects and participating in their financing through fundraising and donations while raising awareness among the general public and doctors about the syndrome.

Webpages: https://www.lespetitsmecp2.org
Email: mecp2association@gmail.com
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