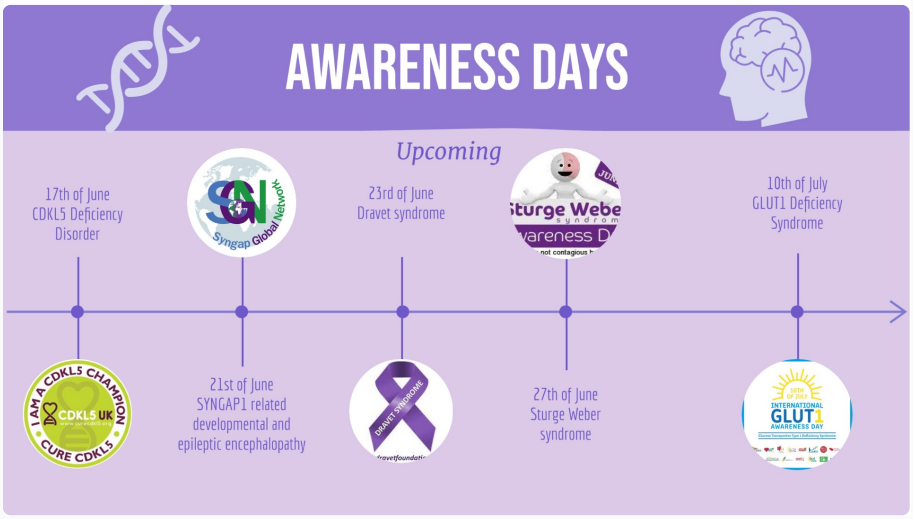
ePAG EpiCARE Newsletter
June 2023

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



ePAG EpiCARE news

During the EpiCARE AGM held in Utrecht from May 29th to 31st ePAG EpiCARE held the hybrid meeting!
After a while, ePAGs finally met in person and discussed the future work plan and activities. We also had the elections, and we proudly present our chair Isabella Brambilla and new co-chair Irena Bibić!
We can't wait to continue the work and make every rare and complex epilepsies

heard! Stay tuned for the upcoming activities!

Meet our ePAGs

José Ángel Aibar is involved in the activities of the Spanish organisation Dravet Syndrome Foundation, where he has served as president since June 2018. Due to his son's illness, José believes in the importance of patient organisations in improving diagnosis, treatment, care and support for better outcomes for all patients with rare and complex epilepsies, including the Dravet syndrome.

José Ángel Aibar presentation video

News

New leaflet translations

Visit EpiCARE's website to download the leaflets now available in various languages including Italian, Romanian, Croatian, Portuguese, German, Norwegian, and Spanish. Leaflet translation is ongoing and there will be more published ones soon!

If you are interested in translating the leaflet for your condition, please contact: epag.epicare@gmail.com

Upcoming events

Gentle reminder on GNAO1 European Conference 2023

GNAO1 European conference, organized by the association Famiglie GNAO1, will be held on June 16th-17th in Rome, Italy!
Program and registration

Meeting of SYNGAP1 families by Famiglie Syngap1 Italia

The first meeting of the Syngap1 families will take place in Rome, Italy on 20th and 21st of June 2023.
The APS FAMIGLIE SYNGAP1 ITALIA association is organising the first national Congress for healthcare professionals, researchers and all Italian families to create a moment of discussion and knowledge and information sharing, and supporting and advising families!
June 21st is the date chosen internationally to raise awareness for this rare genetic anomaly.
Full program
Registration

5th GRIN Europe conference

It is our great pleasure to inform you about the upcoming 5th GRIN Europe conference, 7-8 October 2023, organized by our GRIN Europe association, formerly known as GRIN2B Europe. Barcelona is the chosen location for the 2023 conference given its easy access from many parts of Europe.

For this conference there are 13 confirmed speakers from different parts of the world and from different areas of interest in GRIN disorders. Their presentations will be followed by a round-table event where collaborative work and future research discussions will be encouraged.
This conference is without doubt the most important scientific event in Europe for GRIN-related research and is essential to build a support network for families living with GRIN children.
For more information visit GRIN Europe brand new website.

Meet the patients' associations

Alliance Syndrome de Dravet

The Dravet Syndrome Alliance is a French-speaking association of patients and their family affected by Dravet Syndrome. Since 2009, in partnership with professionals from the Rare Epilepsy Reference Centers, ASD has been supporting families, communicating about the disease and supporting research.
Their 300 members represent more than 150 families.
Does your child have Dravet Syndrome? The association supports you by putting you in touch with volunteer parents to share experiences, inviting you to meet at online round tables or local events. It supports you in the purchase of specific equipment (crisis detectors, leisure or educational equipment, anti-choking pillows, refreshing vests, adapted caps, etc.) and in accessing to respites (financial support). Every year, ASD offers you useful training in your daily life with a Dravet patient: administrative training on MDPH files, legal training on family protection and training on care: oral disorders, CAA (alternative and augmented communication, such as PODD), behavioral disorders, ABA…
Each year they organize national meetings where they take stock with specialists on the progress of research and the care adapted for the children. This is also an opportunity to meet each other, share parenting tips and tricks and share good times. This year their 2023 national meeting will take place on November 25th and 26th.

L'Alliance syndrome de Dravet est une association francophone de familles et de proches de personnes atteintes du Syndrome de Dravet.
Depuis 2009, en partenariat avec les professionnels des Centres de Références Epilepsies Rares, ASD soutien des familles, communique sur la maladie et soutien la recherche. Nos 300 membres représentent plus de 150 familles.
Votre enfant est porteur du Syndrome de Dravet ? L'association vous soutient en vous mettant en lien avec des parents bénévoles pour vous écouter et échanger. Elle vous propose de vous rencontrer lors de tables rondes en ligne ou d'évènements locaux. Elle vous soutient dans l'achat de matériel spécifique (détecteurs de crises, matériel de loisir ou pédagogique, oreillers anti-étouffement, gilets rafraichissants, casquettes adaptées…) et pour l'accès au répit (soutien financier). ASD vous propose chaque année des formations utiles dans votre quotidien avec une personne Dravet : des formations administratives sur les dossiers MDPH, juridique sur la protection de la famille et des formations sur les prises en charge : les troubles de l'oralité, la CAA (communication alternative et améliorée, telle que le PODD), les troubles du comportement, l'ABA…
Chaque année nous organisons des rencontres nationales où nous faisons le point avec les spécialistes sur l'avancée de la recherche et les prises en charges adaptées pour nos enfants. C'est l'occasion de nous rencontrer, d'échanger nos trucs et astuces de parents et de partager de bons moments. Cette année nos rencontres nationales 2023 auront lieu le 25 et le 26 novembre.

Contacts and social media:
Website: www.dravet.fr
Email: contact@dravet.fr
Facebook: facebook.com/alliancesyndromededravet
Twitter: twitter.com/alliancedravet
Membership for Dravet individuals, parents and immediate family
Membership for relatives and supporters

CDKL5 Deutschland e.V.

The non-profit association "CDKL5 Germany e.V." was founded in 2015 by parents whose children are affected by the rare CDKL5 deficiency disorder, physicians and therapists with the aim of bringing CDKL5 families together and raising funds to find a cure for this genetic condition.
The association has been actively working since January 2016 and is pursuing its goals: networking, educational and public relations work and raising funds for research for CDKL5 deficiency disorder. The association CDKL5 Deutschland e.V. offers all affected families in Germany support and help in difficult situations. They connect the families via social media and offer a platform for exchanging experiences regarding therapies and aids. In addition to the annual family conferences, the association organizes regular meetings and is also in close contact with international patient groups. Their most important message to all those affected is: You are not alone! Since the clinical picture CDKL5 is still relatively unknown, CDKL5 Deutschland e.V. has made it its goal to conduct educational work among physicians, therapists and the public. Around the world today there are research projects looking for a cure for CDKL5. Various paths are taken, and German association supports promising projects by collecting donations. They are in close contact with other associations of the international CDKL5 Alliance in order to promote successful research teams in the long term.
For German speaking families, have a look on the introduction video of the association.

Contacts and social media
Website: www.cdkl5-verein.de/
Email: Info@cdkl5-Verein.de
Facebook
Instagram
Twitter
YouTube

Association for Rare Diseases in Children "Life"

The association Life is very active in raising awareness about the problems of rare diseases, providing support in medical equipment education as well as improving the position in society of both those suffering from rare diseases and their families in Serbia where it is registered.

Život
Udruženje građana za borbu protiv retkih bolesti kod dece

The biggest achievement of the association is the initiative to adopt the Law on Prevention and Diagnosis of Genetic Diseases, Genetically Conditioned Anomalies and Rare Diseases, the so-called Zoya's Law. This law is named after the girl Zoja Mirosavljević, who died of Batten's disease in 2013 at the age of nine. Zoja's law had great support from citizens, the Parlament of the Republic of Serbia, the media and the public. On January 23rd, 2015, the law was unanimously adopted by the Assembly of the Republic of Serbia. From 2020. the internet platform - Rare diseases database has been active. The Rare diseases database is a source of information for doctors, patients and their family members. The search for rare diseases is enabled on the page, where you can read more about the requested disease in Serbian, Macedonian, Croatian and English. The database requires daily updates as it has about 7.000 rare diseases. Also, from the activities, we especially highlight the creation of the online edition of the first and only magazine on rare diseases in the Balkans „Word for Life", which has existed since 2015. "Word for Life" received the great European award of the European Organization for Rare Diseases Black Pearl Award 2018. In addition to the constant work on the portal of the Rare Diseases Database, the planned activities of our association are the Academy for Patients and Patients' Advocates 2022., Regional Conference Rare Diseases Database 2022. as well as organizing educational webinars for doctors and educational webinars for patients.

Contacts and social media:
Website: www.zivotorg.org/
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