European Patient Advocacy Group

ePAG EpiCARE Newsletter
February 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

International Epilepsy Day

On February 12th, we came together to recognize International Epilepsy Day, a global initiative aimed at raising awareness about epilepsy, supporting those affected by the condition, and promoting understanding and acceptance within our communities.
Understanding Epilepsy

Epilepsy is a neurological disorder characterized by recurrent seizures, which can vary in type and severity. It affects people of all ages and backgrounds, impacting not only individuals living with epilepsy but also their families, friends, and caregivers.

Shattering Myths and Stigma

Despite being one of the most common neurological conditions worldwide, epilepsy is still shrouded in myths and misconceptions. International Epilepsy Day provides an opportunity to dispel these myths, challenge stigma, and foster a more inclusive and supportive environment for those affected by epilepsy.

Supporting Those Affected

Living with epilepsy can be challenging, but with the right support and resources, individuals can lead fulfilling lives. Let's reaffirm our commitment to supporting those affected by epilepsy by offering understanding, empathy, and encouragement.

Promoting Awareness and Education

Education is key to improving the lives of people with epilepsy. By increasing awareness, promoting education, and advocating for access to quality healthcare and treatment options, we can empower individuals with epilepsy to manage their condition effectively and live to their fullest potential.

Advocating for Epilepsy Research

Advancements in epilepsy research are crucial for developing better treatments, improving seizure control, and ultimately finding a cure.

Final Thoughts

As we mark International Epilepsy Day, let's stand together in solidarity with the millions of people affected by epilepsy worldwide. Let's work towards a future where epilepsy is better understood, stigma is eliminated, and everyone living with the condition receives the support and care they need.

CHD2 Related Disorders

On February 2nd we marked CHD2-related disorders Awareness Day, a group of rare genetic conditions that can profoundly impact individuals and their families. Join us as we raise awareness, support those affected, and advocate for better understanding and resources.

Understanding CHD2-Related Disorders

CHD2-related disorders are caused by mutations in the CHD2 gene. These disorders encompass a spectrum of neurological and developmental challenges, including epilepsy, intellectual disability, developmental delays, behavioral issues, and more.

Challenges Faced by Individuals and Families

Living with a CHD2-related disorder presents numerous challenges for affected individuals and their families. The complex nature of these conditions, coupled with the variability in symptoms and outcomes, can make diagnosis and management difficult. Families often navigate a journey filled with uncertainty, seeking answers and support along the way.

The Importance of Awareness and Support

Raising awareness about CHD2-related disorders is essential for early recognition, accurate diagnosis, and improved support for affected individuals and families. By increasing understanding within our communities, we can ensure that those living with these conditions receive the care, resources, and support they need to thrive.

Advocating for Research and Resources

Advancements in research are critical for deepening our understanding of CHD2-related disorders and developing targeted therapies and interventions. Advocacy plays a vital role in driving research forward, and promoting collaboration among researchers, clinicians, and affected families.

Angelman Syndrome

Angelman syndrome

February 15th is a day to raise awareness for Angelman Syndrome, a rare neurogenetic disorder that affects individuals worldwide. Join us as we shine a light on Angelman Syndrome, support those affected, and advocate for better understanding and resources.

Understanding Angelman Syndrome

Angelman Syndrome is a complex condition caused by genetic abnormalities on chromosome 15. It is characterized by developmental delays, intellectual disability, seizures,

speech impairments, and a unique happy demeanor. Individuals with Angelman Syndrome often face challenges with movement and balance, along with sleep disturbances.

Challenges Faced by Individuals and Families

Living with Angelman Syndrome presents significant challenges for affected individuals and their families. Daily tasks, communication, and managing seizures require specialized care and attention. Families often seek support, information, and resources to navigate the complexities of Angelman Syndrome.

The Importance of Awareness and Support

Raising awareness about Angelman Syndrome is crucial for early diagnosis, access to appropriate care, and improved quality of life. By increasing understanding within our communities, we can ensure that those living with Angelman Syndrome receive the support, resources, and empathy they need.

Advocating for Research and Resources

Advancements in research are essential for deepening our understanding of Angelman Syndrome and developing targeted treatments.

SCN8A Related Epilepsies

On February 9th, we came together to shed light on SCN8A-related epilepsy, a rare and complex form of epilepsy that affects individuals worldwide.

SCN8A-related epilepsy is a genetic disorder caused by mutations in the SCN8A gene, which encodes a sodium channel critical for proper brain function. This condition can manifest with various seizure types, developmental delays, intellectual disability, and other neurological challenges.

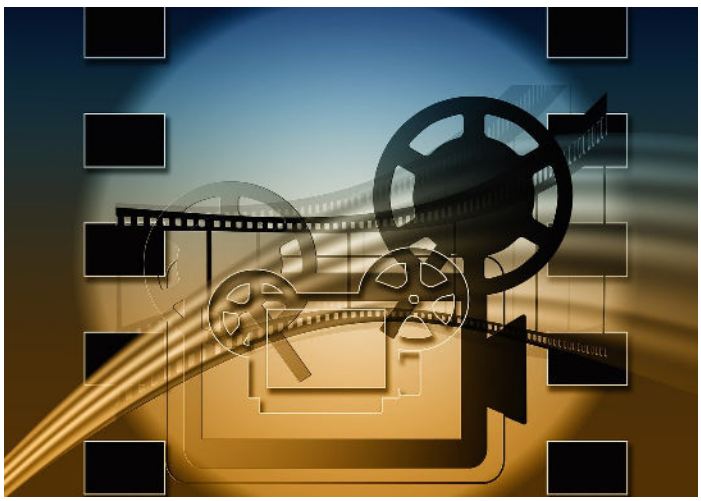
Challenges

Living with SCN8A-related epilepsy presents significant challenges for affected individuals and their families. Seizure management, developmental delays, and navigating the healthcare system can be overwhelming. Families often seek support, information, and resources to help them along their journey.

The Importance of Awareness and Support

Raising awareness about SCN8A-related epilepsy is crucial for early diagnosis, access to appropriate care, and improved outcomes. By increasing understanding within our communities, we can ensure that those living with this condition receive the support, resources, and empathy they need.

Events



New Video Released

For International Epilepsy day and the upcoming Rare Disease Day EpiCARE ePAG have prepared an awareness video.
It is available to view here.

Save the date for the European Dravet Syndrome Conference 2024
Fundación Síndrome de Dravet is organising a Dravet Syndrome Conference in 2024. Save the 14th and 15th March 2024 in your calendars and join the conference in Madrid.
For preliminary program and registration details please click here.

Meet the patient's associations

Dravet Italia Onlus

DRAVET ITALIA Onlus
Associazione Italiana Sindrome di Dravet Onlus

DRAVET ITALIA ONLUS is an Italian non-profit organization, founded in 2010 to support the research for a rare form of drug-resistant epilepsy called Dravet syndrome. The association was created with the intention of actively improving the quality of life of those children affected by DS. Experienced doctors and parents are united with this goal. This vital partnership has already given life internationally, to events that have contributed to progress in understanding and treatment of the syndrome. Our aim is to support the research and to turn hope into reality.

Main Goals:

- Provide financial support for scientific research on Dravet Syndrome, financing in particular valid research projects and related grants;
- Spread awareness of the study and research activities carried out in the national and international fields;
- Raise public awareness of institutions, both national and international, and to develop a rapport with the relevant institutional bodies;
- Encourage development of orphan drugs;
- Improve knowledge of Dravet Syndrome;
- Carry out any and all activities that complement or are necessary to reach the associated goals.
- Promote and organize the necessary fundraising through initiatives and events, using the volunteer work of members.

Highlighted project:

Dravet Registry: Creation of a first Registry (RESIDRAS) - www.dravet-registry.com of Dravet Syndrome and other syndromes correlated with mutations of Gene SCN1A and PCDH19, and its development at a European and International level (PLATFORM-RESIDRAS). Registries are an essential element for epidemiological clinical research aimed at the development of new treatment solutions and at improving the quality of life for patients and their families.

Dravet Diary: is an electronic diary produced for people with epilepsy and in particular the rare and complex form like Dravet Syndrome'. The purpose of Dravet Diary is to carefully document seizures, the state of health and current therapy and to prepare this information for easy sending to their specialists, who can then be updated on the progress of the condition. An effective tool, dedicated to families involved in the care of their children, teenagers and adults, to try to improve the management of the disease as a whole and at the same time provide doctors with accurate and up-to-date data. Improving doctor-patient communication. The Dravet Diary is available free of charge, in several languages, on the AppStore, Google Store and by web www.dravetdiary.com

Contact and social media:

DRAVET ITALIA ONLUS - Associazione Italiana Sindrome di Dravet

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YouTube: Dravet Italia Onlus/YouTube

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