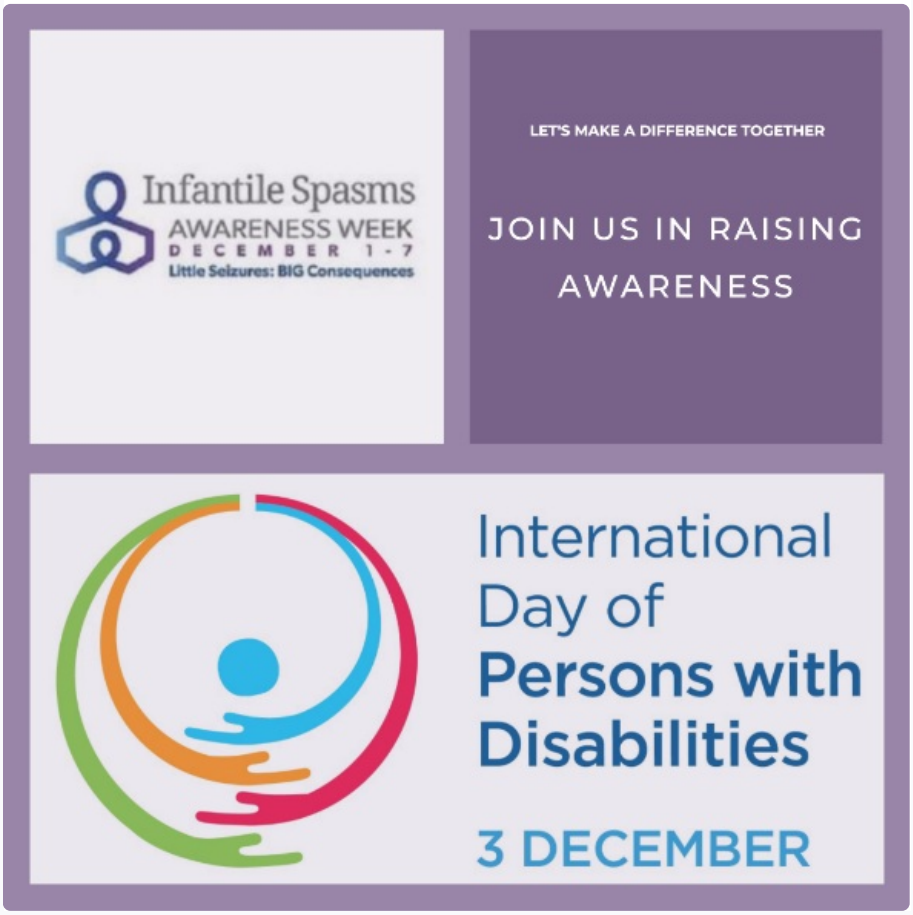
European Patient Advocacy Group

ePAG EpiCARE Newsletter
December 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



Infantile Epileptic Spasms Syndrome Awareness Week

From December 1st to 7th, we shed the light on Infantile Epileptic Spasms Syndrome!
What is Infantile Epileptic Spasms Syndrome (IES)?
IESS is a rare and severe form of epilepsy that typically begins in infancy, usually between the ages of 4 and 8 months. It's characterized by specific seizure patterns, often appearing as sudden, repeated, and frequent spasms or jerks in the arms, legs, or torso. These spasms can be subtle and mistaken for other movements, making diagnosis challenging.
Why Raise Awareness?
Raising awareness about IESS is crucial as early detection and intervention are vital for better outcomes. Many caregivers, parents, and even some medical professionals

may not recognize the signs of IESS, leading to delayed diagnosis and treatment. By spreading awareness, we can help more families recognize symptoms early and seek appropriate medical care promptly.

Impact on Families and Individuals

Living with IESS can be incredibly challenging for both the affected child and their family. The unpredictability of seizures, the strain on daily life, and the emotional toll it takes on everyone involved can be overwhelming. Increased awareness can help create a more supportive environment for affected families and foster understanding in communities.

How Can You Help?

Spread the Word: Share information about IESS on social media, within your community, or among friends and family. Education is key!

Support Affected Families: Offer support, understanding, and empathy to families dealing with IESS. Small gestures of kindness can make a huge difference.

Advocate for Early Diagnosis and Treatment: Encourage early screening and diagnosis for infants showing potential symptoms of IES. Early intervention can significantly improve outcomes.

[To learn more about IESS have a look at EpiCARE leaflets.]

International Day of Persons with disabilities

On the International Day of Persons with Disabilities, we shed a light on the multifaceted challenges faced by individuals battling rare and complex epilepsies, often compounded by numerous comorbidities.

Understanding Rare and Complex Epilepsies

Rare and complex epilepsies encompass a spectrum of disorders characterized by seizures that are difficult to control and often intertwined with various other health complications. These conditions not only present frequent and severe seizures but also introduce a multitude of comorbidities that significantly impact the lives of those affected.

The Burden of Comorbidities

Individuals with rare and complex epilepsies frequently contend with a range of associated comorbidities, including cognitive impairment, developmental delays, behavioural challenges, motor difficulties, sleep disturbances, and more. These comorbidities vary in severity and can profoundly affect an individual's quality of life, independence, and daily functioning.

Importance of Comprehensive Care and Support

Addressing the needs of those living with rare and complex epilepsies requires a holistic approach. Access to specialized healthcare, therapies tailored to specific challenges, and comprehensive support services are essential in improving the lives of individuals with these conditions. It's crucial to recognize and support not just the epilepsy itself but also the diverse array of comorbidities that accompany it.

Advocating for Inclusivity and Understanding

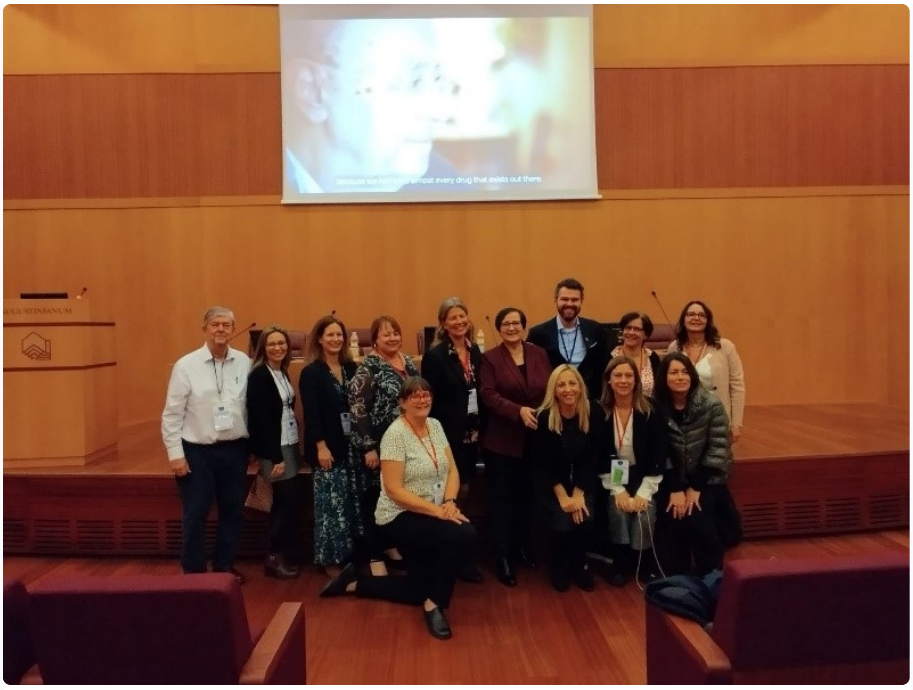
On this day, we should pledge to foster a more inclusive society that embraces the diversity and unique needs of individuals with rare and complex epilepsies and their associated comorbidities. By raising awareness, advocating for better resources, and promoting understanding and acceptance, we can create a more supportive environment for all.

Final Thoughts

As we celebrate diversity and strive for inclusivity, let's remember to stand in solidarity with individuals battling rare and complex epilepsies and their associated comorbidities. Let's work together to ensure they have the resources, support, and understanding they need to lead fulfilling lives.

Events

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



During the workshop, our ePAGs have led a session: Epileptic Seizures in neurological disorders: the role of Patient Advocates.
Carol-Anne Partridge has talked about pharmacological therapies and its impact on daily life, Rosaria Vavassori raised the issue of neurological and neuropsychological comorbidities, and Maryse Arendt wrapped up the session with the importance and necessity of multidisciplinary and holistic approach.
We thank all the participants for taking their time in answering our question about the therapy and its side effects and the multidisciplinary care, and for raising a great discussion!

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

Tess Research Foundation for SLC13A5 Epilepsy

TESS Research Foundation is determined to improve the lives of those affected by SLC13A5 Epilepsy. We do this by funding research, spreading awareness, and supporting children with SLC13A5 Epilepsy and their families.

Events
- Our SLC13A5 Awareness Day is May 13

Highlighted projects
- TESS Scientific Director, Tanya Brown, PhD recently presented preliminary data from the SLC13A5 Epilepsy Natural History Study at the RESOLUTE meeting in Austria
- Our Scientific Literacy Program helps families understand ongoing research topics. This program includes a Science Simplified Blog and a newsletter that summarizes recent publications for families.
- Ongoing research funding for early career and collaborative science about SLC13A5 Epilepsy (Citrate Transporter Disorder).

Activities
We are hosting a SLC13A5 International Research Roundtable August 2nd-3rd, 2024. This will be a hybrid meeting with in person attendees meeting at Brown University. This is for both scientists, healthcare professionals and affected families.

Social media
Facebook: https://www.facebook.com/TESSresearch/
Instagram: https://www.instagram.com/tessresearch/
X (formerly Twitter): https://twitter.com/@TessResearch
LinkedIn: https://www.linkedin.com/company/tess-research-foundation
YouTube:
https://www.youtube.com/channel/UC91oK1D0Lyhcny9anjBTrSw/featured

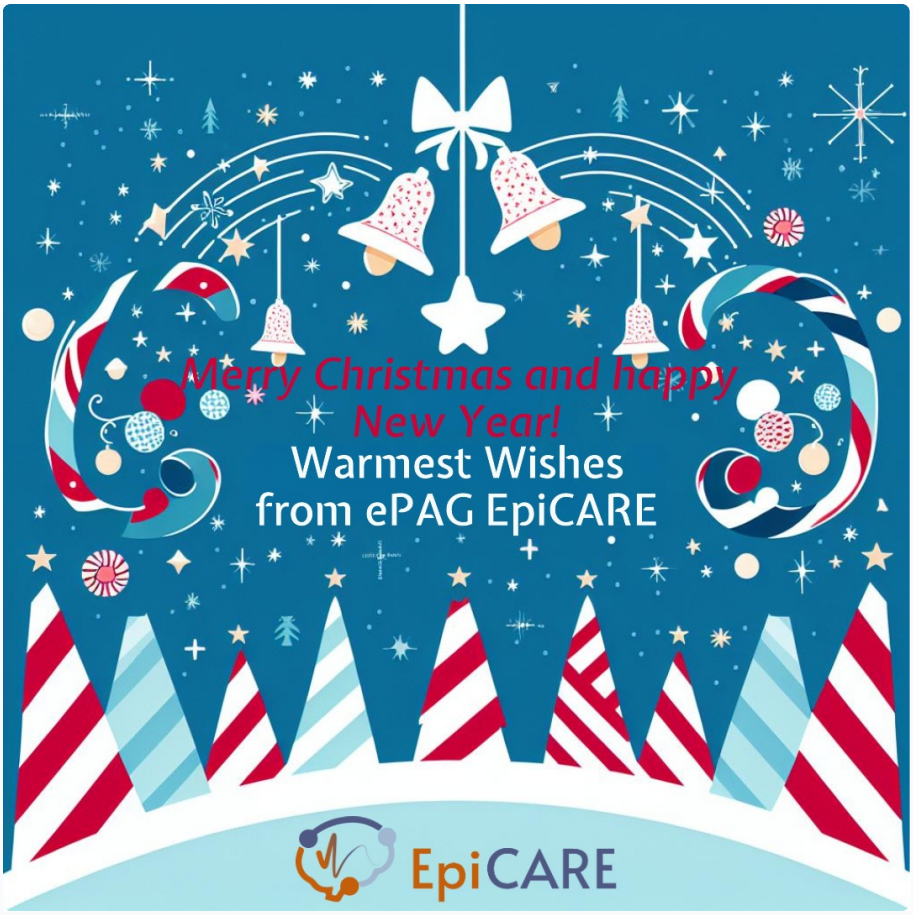
For more information, please visit our website: tessresearch.org

SCN2A Georgia

SCN2A Georgian Association was established March 1st 2021. The main aim of the organization is to help Georgian SCN2A families to connect with each other and to be stronger. For every rare disease family, it's very important to realize that they aren't alone against the disease. Another reason was to raise awareness towards healthcare professionals. Most of them haven't even heard about SCN2A Gene Disorders, and we wanted Georgian SCN2A kids also to have representative in global SCN2A Family

SCN2A Georgian Association is running a Facebook page. All the news about SCN2A is shared there.
Since November 2021 SCN2A Georgian Association is the member of EURORDIS. Its chair has graduated Winter School 2022 this March. EURORDIS helped the association to realize the importance of Patient Advocate groups.
For now, we are trying to raise awareness towards rare diseases, to help break the stigma and to communicate with government about the needs for rare disease patients and families.
For the first time in Georgia there will be the Commission for Rare and Genetic diseases and we're honored to represent rare disease families.
SCN2A Georgian Association is the member of Global Genes since March 2022.

Social media
Facebook: facebook.com/SCN2AGeorgia



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