



European Patient Advocacy Group

ePAG EpiCARE Newsletter June 2025

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

Each year, awareness days shine a light on rare and complex epilepsies, helping to amplify the voices of those affected. These days are vital in driving research, improving care, and fostering a more inclusive society.

We need your support! Whether it's sharing stories, wearing awareness colours, or engaging in local events, every action counts. Join us in spreading awareness and advocating for better understanding and resources.

Stay tuned for key dates and ways to get involved. **Together, we can make a difference!**





In Loving Memory of



Charlotte Dravet

It is with profound sadness and deep respect that we mark the passing of Dr. Charlotte Dravet.

Dr. Dravet was not only a pioneering figure in epilepsy research known worldwide for describing the condition that would later bear her name, Dravet syndrome, but also a compassionate physician who remained deeply committed to the human side of medicine throughout her long and impactful career.

Her legacy extends far beyond the walls of hospitals and research institutions. Dr. Dravet was an unwavering advocate for patients and their families. She believed fiercely that medical care must be built on empathy, listening, and partnership. She stood beside parents in their hardest moments, and she never stopped learning from the children she treated. Her warmth, humility, and dedication were a source of strength and comfort to thousands around the world.

In her later years, Dr. Dravet devoted much of her time to supporting patient organizations. She generously gave her knowledge, time, and heart to families and advocacy groups across the globe. She believed in the power of community, the importance of education, and the right of every child to a better future.

Her legacy lives on in every patient who now receives an earlier diagnosis, in every organization empowered by her presence, and in every scientific advancement built on the foundation she laid. She has left an indelible imprint on the world, one of empathy, excellence, and enduring commitment to the people she so dearly cared for.

We mourn her passing, but more importantly, we celebrate a life lived with purpose and love.

Thank you, Dr. Dravet. You will never be forgotten.

NEWS

Join the CREA Alliance – A European Voice for Rare and Complex Epilepsies

The **Complex and Rare Epilepsies Alliance (CREA)** is a newly formed AISBL based in Brussels, Belgium, and a growing European network of patient organisations, with 9 founding members and 41 member organisations to date, working to improve the lives of those affected by rare and complex epilepsies. Officially presented in Barcelona in May 2025 with the support of EpiCARE, CREA brings together different stakeholders to address shared challenges, from access to diagnosis and care, to education, social inclusion, and health equity.

Why join CREA?

By becoming part of the alliance, your organisation gains access to:

- A collaborative advocacy platform
- Joint research and policy initiatives
- Educational resources and cross-border cooperation
- A community rooted in solidarity, inclusivity, and co-creation

CREA operates through three pillars: research, policy and branding, and membership & collaboration. Two types of membership are available: full (with voting rights) and associate (advisory and participative).

For more information or to join CREA, please contact:

✉ creaalliance@gmail.com

EVENTS

1st meeting Rare and Complex Epilepsies Patient Advocacy Organisations and EpiCARE ePAG – hybrid event

On May 9th–10th, 2025, a milestone gathering took place in Barcelona, uniting representatives of rare and complex epilepsy communities from across Europe. Organised with the support of ERN EpiCARE, the meeting marked the formal presentation of the Complex and Rare Epilepsies Alliance (CREA), a collaborative network of organisations working together for equity in care, research, and quality of life.

Event Highlights

The event was opened by Isabella Brambilla, CREA President, and Prof. Alexis Arzimanoglou, EpiCARE ERN Coordinator, who emphasised the importance of connecting experts and patient advocates across borders.

Core sessions included:

- **What is CREA?** – introducing CREA’s mission, structure, and values
- **Branding the Community (E+)** – creating a shared identity for visibility and solidarity
- **Research in Rare Epilepsies** – launching a pan-European needs survey
- **CREA Agenda 2025/2026** – outlining joint actions, campaigns, and strategic goals
- **Mental Health Workshop** – developing tools for emotional resilience and family support

Key Developments

The **E+ branding** initiative strengthens community recognition and unity.

A European-wide patient and caregiver survey (2025–2026) is underway to gather data that will inform advocacy and improve care pathways.

CREA's strategic agenda includes participation in major events like the 2025 Lisbon International Epilepsy Congress and 2026 Athens European Epilepsy Congress, and a focus on international awareness campaigns and policymaker engagement.

Mental Health Matters - a dedicated workshop underscored the mental health toll on families affected by rare epilepsies. Key takeaways:

- Need for holistic care models that address emotional wellbeing
- Importance of resilience-building tools, caregiver support, and community resources
- Plans to implement a Mental Health Toolkit tailored for national and local contexts

CREA invites all stakeholders to join the movement. For more information or to get involved, visit CREA or contact: ✉ creaalliance@gmail.com

Let's build a Europe where no person living with a rare or complex epilepsy is left behind.



EpiCARE's Annual General Assembly

At the EpiCARE ERN Annual General Meeting in Salzburg (10th-12th of June 2025), ePAG EpiCARE members presented the outcomes of the recent CREA meeting held in Barcelona and highlighted the growing momentum within the rare and complex epilepsy community.

Key Milestones and Initiatives:

- Launch of E+, a shared branding identity for all rare and complex epilepsies designed to strengthen visibility, emotional resonance, and connection across the community.
- A co-creation session helped define storytelling goals for a future campaign, emphasizing resilience, lived experience, and unity.

- A community survey, co-developed with clinicians, is set to launch before the end of 2025. It will collect anonymised data on access to care, comorbidities, and daily challenges. The results will inform scientific publications and advocacy efforts.
- Poster session featured contributions from 33 patient organisations, now publicly available via the [EpiCARE website](#) to foster cross-border learning and collaboration.



A Mental Health Workshop, in collaboration with EURORDIS, explored the needs of not only patients but also families and caregivers – focusing on building practical tools and emotional resilience.

What's Next?

CREA and its members will participate in the 36th International Epilepsy Congress in Lisbon.

The unveiling of a new visual identity is planned marking a bold and unifying step forward.

Continued expansion of collaborative projects, campaigns, and patient-centered initiatives.

The message is clear: A new chapter has begun. Are you ready to be part of it?

For more information about CREA and how to join, contact: creaalliance@gmail.com



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