EpiCARE EPAG Advocates that actively participate in meetings, working groups and initiatives.

Additional EpiCARE EPAG Representatives that follow in our work and are invited to participate/provide input from time-to-time.
Let us introduce ourselves...
Let us introduce ourselves…

Isabella Brambilla

President Dravet Italia Onlus
President Dravet Syndrome European Federation
Coordinator EPAG-ERN Rare and Complex Epilepsy

DRAVET ITALIA Onlus
Associazione Italiana Sindrome di Dravet Onlus
Working Group Involvement

**Active**
- WP10 Dietary Treatments
- WPI eDatabase
- WPII Guidelines

- Carol-Ann / Barbara
- Allison / Isabella
- Isabella / Myra

**New!**
- WP3 Neuroimaging
- WP4 Neurophysiology
- WP7 Targeted Medical Therapies
- WP8 E-pilepsy
- WP9 Neonatal Seizures

- Emma N
- Isabella
- Barbara / Katia
- Emma N
- Sarka
Working Group Involvement

Inactive

- WP2 Lab Diagnostics
- WP5 Neuropsychology
- WP6 Neuropathology
- WP11 Dissemination

We would like to work with you!

“We would like to work with you!”

“Nothing about us, without us”
Can you help us extend our EPAG reach?

Reach

EpiCARE Centres (28 centres, 13 countries)  EPAG reps (11 reps, 6 Countries)
Our Strategic Priorities

EpiCARE to focus on the origin of the rare disease, finding more effective, targeted treatments for epilepsy and beyond, looking at the holistic needs of patients with rare and complex epilepsies specifically behaviour, development and seizure control.

- Take a holistic approach
- Find a cure, find more effective treatment!
- Build personal capacity to lead healthy and independent lives
- More research ...!
- Spread the knowledge of the network
- Education, education, education
Method

✓ ePAC Advocates completed a mapping exercise of the needs of each rare inherited syndrome they represent, across the different stages of the patient journey.

✓ Stages of patient journey progress from first symptom, pre-diagnosis, diagnosis, first treatment, surgery, surveillance and follow-up care.

✓ Patient needs at each stage of the journey are referenced under three levels - clinical presentation, patient needs, recommendations on ideal care.

✓ Summarised in visual diagram of a patient journey, for easy reference.

✓ All patient journeys are to be reviewed together, to identify needs that are common for all rare diseases, for all genturis syndromes and those that are specific to individual syndromes.

✓ Each patient journey will be reviewed by members of their respective communities before being clinically validated by GENTURIS Thematic.
Collaboration across ERN EPAG’s
• Outcomes and Guidelines  
• Research and Registries  
• Training and Education  
• Digital Health and Cross border  
• Communications Roadmap  
• Integration into National Health Systems
How we can help…

- Extend our EPAG network/reach
- Assist with dissemination to patients/patient families
- Utilise our professional skills in WP activities
- Help with Integration of ERN’s into National Health Systems
- Help achieve what patients want

Bring the patient voice to the table
Thank you!

epag.epicare@gmail.com