



European Patient Advocacy Group

EpiCARE AGM

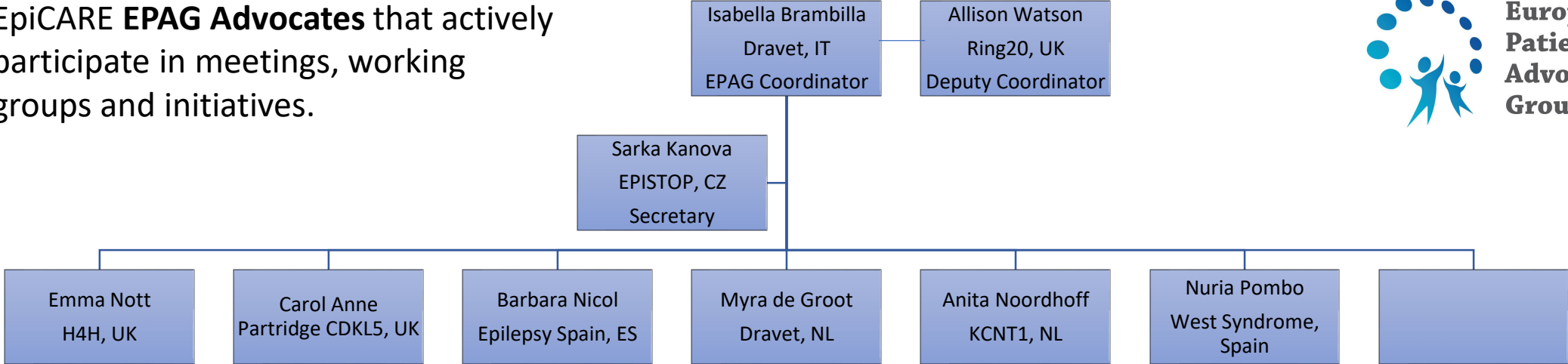
London February 2019

Allison Watson & Isabella Brambilla



**European
Patient
Advocacy
Group**

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.

Your EpiCARE EPAG

Let us introduce ourselves...



**European
Patient
Advocacy
Group**



European
Patient
Advocacy
Group

ERN EpiCARE

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



draveteurope

Dravet Syndrome European Federation

Working Group Involvement



Active

- WP10 Dietary Treatments ➤ Carol-Ann / Barbara
- WPI eDatabase ➤ Allison / Isabella
- WP11 Guidelines ➤ Isabella / Myra

New!

- WP3 Neuroimaging ➤ Emma N
- WP4 Neurophysiology ➤ Isabella
- WP7 Targeted Medical Therapies ➤ Barbara / Katia
- WP8 E-pilepsy ➤ Emma N
- WP9 Neonatal Seizures ➤ Sarka

Working Group Involvement



Inactive

- WP2 Lab Diagnostics
- WP5 Neuropsychology
- WP6 Neuropathology
- WP11 Dissemination
- WP12 Education and Training
- WP13 Research
- WP14 Clinical Trials

We would like to work with you!

“Nothing about us, without us”

Reach



EpiCARE Centres (28 centres, 13 countries)

EPAG reps (11 reps, 6 Countries)

Can you help us extend our EPAG reach?



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Our Strategic Priorities



**European
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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.

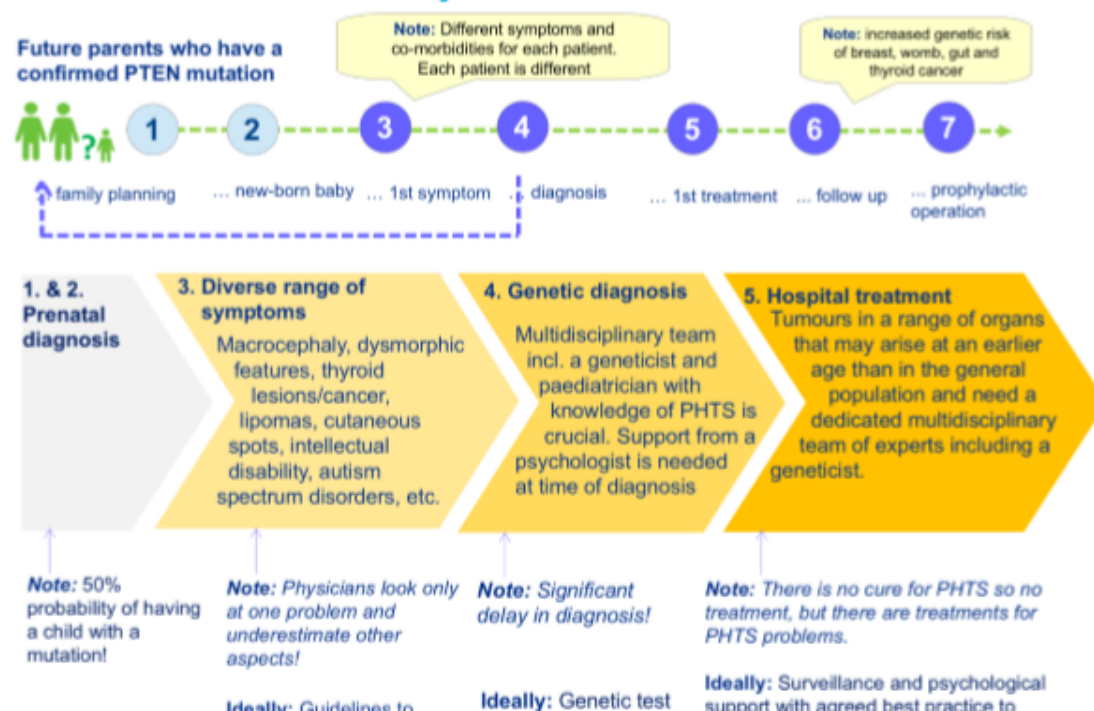
- Take a holistic approach
- Find a cure, find more effective treatment!
- Build personal capacity to lead healthy and independent lives
- More research ...!
- Spread the knowledge of the network
- Education, education, education



Method

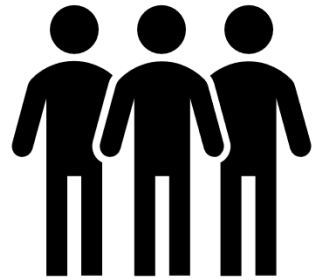
- ✓ ePAG Advocates completed a mapping exercise of the needs of each rare inherited syndrome they represent, across the different stages of the patient journey
- ✓ Stages of patient journey progress from first symptom, pre-diagnosis, diagnosis, first treatment, surgery, surveillance and follow-up care
- ✓ 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

Patient Journey Example: PTEN Hamartoma Tumour Syndrome





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Collaboration
across ERN
EPAG's

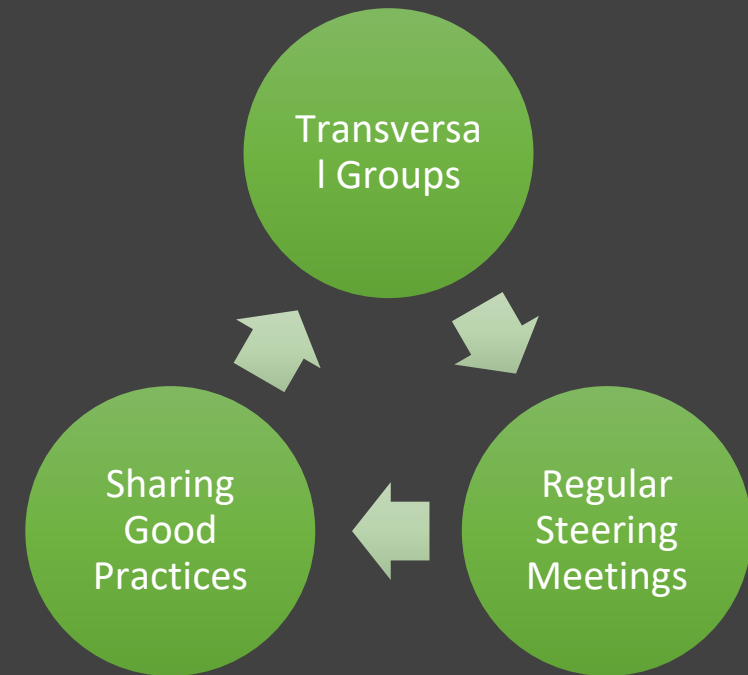




European Patient Advocacy Group

- 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



**European
Patient
Advocacy
Group**

Bring the
patient
voice to the
table





European Patient Advocacy Group

Thank you!

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