# EpiCARE ANNUAL MEETING ANNUAL MEETING PROGRAM Barcelona, Spain June, 17th - 19th 2024





# **ANNUAL MEETING AGENDA**

#### Monday, June 17th 2024

8h30-10h30	Meeting of the Executive Committee	
10h30-11h00	Coffee break	
11h00-13h00	Meeting of the Executive Committee	
14h00	Opening ERN EpiCARE Annual Meeting	
	Meetings of EpiCARE work groups - Session 1: (parallel sessions)	
14h00-15h30	<ul> <li>Pre-surgical evaluations &amp; surgery (WG8) - Sala Güell</li> <li>Neonatal Seizures &amp; Epilepsies (WG9) - Sala Tibidabo</li> <li>National Networks &amp; JARDIN project (WG10) - Sala Cervantes</li> <li>GenEp Algorithm - Sala Montjuïc</li> </ul>	
15h45-17h15	<ul> <li>Meetings of EpiCARE work groups - Session 2: (parallel sessions)</li> <li>Neuroimaging (WG3) - Sala Montjuïc</li> <li>Neurophysiology (WG4) - Sala Tibidabo</li> <li>Clinical trials &amp; Targeted therapies (WG7) - Sala Cervantes</li> <li>Education &amp; Training (WG14) - Sala Güell</li> </ul>	
17h30-19h00	<ul> <li>Meetings of EpiCARE work groups - Session 3: (parallel sessions)</li> <li>Clinical Genetics (WG2) &amp; Genetic Research (WG16) (joint meeting) - Sala Tibidabo</li> <li>Neuropsychology (WG5) &amp; Epilepsy Beyond Seizures (WG18) (joint meeting) - Sala Güell</li> <li>Neuropathology (WG6) - Sala Montjuïc</li> <li>Registries, Data Sharing (WG12), Case discussions / CPMS (W11) (joint meeting) - Sala Cervantes</li> </ul>	
19h30	Networking dinner. Meet us at the hotel's reception at 19h30.	
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## **ANNUAL MEETING AGENDA**

Tuesday, June 18th - General Assembly		
<mark>08h30</mark> -09h45	Welcome and Executive Committee report	
09h45-10h15	EpiCARE centres Performance Indicator System	
10h15-10h45	Coffee Break	
10h45-11h00	Becoming familiar with the version 2.0 CPMS	
11h00- 11h15	The EpiCARE registry: update on SPIDER & next steps	
11h15-12h15	WG 19 Patient Advocates development plan. Q&A to the EpiCARE patient advocates (ePAGs)	
12h15-13h30	Q&A to EpiCARE Work Group leaders on ongoing projects and actions	
13h30-14h45	Networking Buffet lunch	
	Invited lecture: Brain organoids as a model in developmental	
14h45-15h45	epilespy Sandra Acosta Institute of Neurosciences, Pathology and Experimental Therapeutics Dept, University of Barcelona. Functional Neurogenomics Group, Neurodevelopmental Disorders, IDIBELL.	
15h45-16h45	Preparing the Delphi study on definition of Level III-IV Epilepsy Care Centres in Europe. (presented by WG10)	
17h00-18h00	Pharmacological and non-pharmacological interventions in the treatment of Infantile Epileptic Spasms Sd Marietta Papadopoulou WG13 TF leader	
18h00- 18h30	Other topics	
18h30	Free networking evening	

#### Wednesday, June 19th 2024

	Parallel working sessions
09h00-12h30	Patient Advocates (WG19) - Sala Güell
	Guidelines (WG13) - Sala Cervantes
	Neuropsychology Paediatric section (WG5) - Sala Tibidabo
	GenEp Algorithm - Sala Montjuïc
12h30	End of the EpiCARE 2024 Annual Meeting

# **WORKING GROUP SESSIONS**

#### Monday, June 17th 2024

14100-19130 - Meetings of EpiCARE work groups - Session 1		
Pre-surgical evaluations & surgery (WG8) Chairs: Philippe Ryvlin, Sylvain Rheims Liaison: Martin Geroldinger Sala: Güell Link	<ul> <li>Joint Guideline Production on Epilepsy Surgery and Neuromodulation – Status Quo and Protocol Discussion.</li> <li>Cross-WG Topics of Research, Neuroimaging and Neurophysiology.</li> <li>Updates from the Paros Epilepsy Meeting.</li> </ul>	
Neonatal Seizures & Epilepsies (WG9) Chairs: Ronit Pressler, Carmen Fons, Geraldine Boylan Liaison: Nicola Openshaw-Lawrence Sala: Tibidabo Link	<ul> <li>Survey on diagnosing neonatal seizures.</li> <li>Defining seizure burden.</li> <li>Neonatal registry.</li> </ul>	
National Networks & JARDIN Project (WG10) Chairs: Retta Kalviainen, Katarzyna Kotulska Liaison: Belén Trebino Sala: Cervantes Link	<ul> <li>Mapping of the epilepsy care pathways in EU - results of the survey and interviews.</li> <li>Preparing the Delphi study on definition of Level III-IV Epilepsy Care Centres in Europe.</li> </ul>	

GenEp Algorithm Chairs: Marietta Papadopoulou, Stefan Rampp Liaison: Sébile Tchaicha Sala: Montjuïc

**Diagnostic Educational Tool for Genetic Epilepsies** 

#### 15h45-17h15 - Meetings of EpiCARE work groups - Session 2

**Neuroimaging (WG3)** 

Link

Chairs: Petr Marusič, Sophie Adler Liaison: Laura Roig Sala: Montjuïc Link

#### Optimising MRI for epilepsy surgery meetings

- Neuroimaging workshops.
- Radiology re-review for Epilepsy Surgery Meeting.
- MRI post-processing for the Epilepsy Surgery Meeting.
- Survey on harmonisation of MRI protocols in EpiCARE centres.

#### Neurophysiology (WG4)

Chairs: Sandor Beniczky, Elena Tartara Liaison: Laura Roig Sala: Tibidabo Link

#### Update and discussion of new projects:

- Update on the PROMAESIS project.
- Update on the SCORE-ICU project.
- Open discussion about new projects.

## **EpiCARE** WORKING GROUP SESSIONS

## Clinical trials & Targeted therapies (WG7)

Chairs: Rainer Surges. Floor Jansen, Valentina De Giorgis Liaison: Sébile Tchaicha Sala: Cervantes Link

### Support and advice for medical trials and targeted treatment: identification of unmet needs

- Update on actions done (DTA, Webinars, ECET) // Interactive presentation.
- Update on SIG (Special Interest Groups) (10 min each): Tuberous Sclerosis, Methodology of Trials, Ketogenic Diet, Autoimmune disease & N-of-1 Trials.

#### What EpiCARE can do for YOU?

The latest Education & Training updates and news.

- EpiCARE webinars themes and plans for next year. Making webinars a deliverable for each WG
- Mentor Mentee programme.
- Cross ERN activities postgraduate course and webinars.
- ePAG involvement.
- Nurses educational activities.

#### 17h30-19h00 - Meetings of EpiCARE work groups - Session 3

#### Update on WG2 and WG16 activities. Clinical Genetics (WG2) & Genetic • Collaborative genetic Research Webpage. Case Discussions/training sessions. Research (WG16) (joint meeting) Chairs: Rima Nabbout, Rikke Moller, Content of Workshop on Genetics of the epilepsy. • Nexus platform. Gaetan Lesca, Renzo Guerrini • Gene panels use and harmonisation. Liaison: Sébile Tchaicha • Multidisciplinary efforts for optimal genetic testing. Sala: Tibidabo Genetic testing in focal structural and non-structural Link epilepsies. Neuropsychology (WG5) & Epilepsy Group organization, case discussions and common neuropsychological projects. Beyond Seizures (WG18) (joint meeting) Chairs: Christoph Helmstaedter, Andrea Consensus on neuropsychological report forms and Palacio, Morten Lossius, Sergiusz Józwiak coding systems. Liaison: Nicola Openshaw-Lawrence and Belén Trebino SIG (Diagnostic gaps in the assessment of severely Sala: Güell impaired patients PCOMS). Link Neuropathology (WG6) WG Neuropathology Report Chairs: Ingmar Bluemcke, Angelika Mühlebner Our postsurgical case discussions. Liaison: Laura Roig

Sala: Montjuïc Link

- Progress of the LEAT taskforce.
- Possibilities of an open access online classifier.

#### Education & Training (WG14)

Chairs: Maša Malenica, Ronit Pressler Liaison: Martin Geroldinger Sala: Güell Link

# **EpiCARE** WORKING GROUP SESSIONS

## Registries, Data Sharing (WG12), Case discussions / CPMS (W11)

Chairs: Lieven Lagae and Nicola Specchio Liaison: Nicola Openshaw-Lawrence Sala: Cervantes Link Open session to ask your questions on the Registry, Data sharing and Case Discussion processes, to Nicola Openshaw-Lawrence (CPMS Project Manager) and Johanna Van Hulle (Registry and Data Manager). Such as: migration to CPMS 2.0, MRI reviewing, thematic based cased discussion sessions, and up to date lists of experts and expertise.

#### Wednesday, June 19th 2024

#### 09h00-12h30

#### Patient Advocates (WG19)

Chairs: Isabella Brambilla Liaison: Nicola Openshaw-Lawrence, Laura Roig Sala: Güell Link

#### **Guidelines (WG13)**

Chairs: Eugen Trinka, Teia Kobulashvili Liaison: Martin Geroldinger Sala: Cervantes Link

## Neuropsychology Paediatric section (WG5)

Chairs: Andrea Palacio, Anna Lopez Liaison: Nicola Openshaw-Lawrence Sala: Tibidabo Link

#### GenEp Algorithm

Chairs: Marietta Papadopoulou, Stefan Rampp Liaison: Sébile Tchaicha Sala: Montjuïc Link

#### • Patient journeys and leaflets plan.

- Survey for rare and Complex Epilepsy.
- 2025 Face to Face meeting.

#### Pre-surgical evaluation Guidelines WG

- Organizational Aspects and Roles of the WG Members.
- CPG Protocol Finalization and Open Discussion.
- CPG Protocol Next Steps and Work Distribution.
- Next Steps and Timeline.
- A European consensus on Pediatric. Neuropsychological Assessment in pediatric epilepsy surgery candidates.
- Do we have enough standardised instruments. available for remote assessments in children? Pros and cons of online sessions.

Diagnostic Educational Tool for Genetic Epilepsies

For more information visit the EpiCARE INTRANET: https://epi-care.eu/connexion/. If you don't have an account, you can register directly on EpiCARE website. Contact: helpdesk@epi-care.eu