



European  
Reference  
Networks



European  
Reference  
Network  
for rare or low prevalence  
complex diseases

🌐 **Network**  
Epilepsies (ERN EpiCARE)

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# European Reference Network for Rare and Complex Epilepsies



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the European Union

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# What you always wanted to know

The European Reference Network (ERN) EpiCARE is one of the 24 ERNs, funded, by the European Commission. In 2024, 1.619 expert medical teams working in 382 hospitals located in all European Union Member States plus Norway, are accredited as Centres of Expertise by their respective health authorities and the European Commission. They bring together experts from different disciplines and specialities. Their role, as networks, is to support all possible interactions between the medical teams, in each area of disease, and to facilitate collaboration with patient advocates at all levels (knowledge generation; fostering research; producing guidelines and clinical recommendations; support the development of national networks of expertise; ...).

In the seven years since its launch in 2017, the **ERN for Rare and Complex Epilepsies, EpiCARE**, has developed strong collaborations between epilepsy specialist departments: 50 accredited members, representing nearly 60 medical teams in 24/27 EU countries and Norway; other collaborating medical teams and individual experts within the European region, such as the UK, Switzerland, Ireland, Greece, Bulgaria, and others. The medical teams with expertise in epilepsy care are multidisciplinary, composed of adult and child neurologists, working in close collaboration with other specialities: neuroradiologists, neurophysiologists, geneticists, neuropsychologists, neuropathologists, neurosurgeons etc. as well as dieticians, epilepsy nurses and EEG technicians.

The main challenge when developing a trans-boarder EU health care network for rare and complex epilepsies derive from the nature of the area of disease.

Indeed, the epilepsies are considered a “spectrum disorder” because of the different causes, different seizure types (symptoms), its ability to vary in severity and impact from person to person, and its range of co-existing conditions. There are also, many different types of epilepsy, resulting from a variety of causes. However, **all types of epilepsies initially manifest themselves with epileptic seizures**, a common symptom not always allowing an easy recognition of a potentially rare or complex epilepsy-disease. This is a significant specificity of ERN EpiCARE when compared to other ERNs. EpiCARE is dealing with more than 160 rare forms of epilepsy, a number steadily augmenting as new forms of genetic epilepsies are identified every year.

Added to these rare epilepsies are the highly complex cases of focal epilepsies that could benefit from a surgical treatment. This treatment option can be proposed to patients concerned only after a long pre-surgical evaluation, a process assessing eligibility to a surgical treatment, an evaluation that can only be performed by multidisciplinary medical and surgical hospital-based teams.

The above-mentioned specificities are reflected in **the structure of EpiCARE**. Compared to other ERNs, EpiCARE could not be structured per individual or grouped rare or complex diseases.

Consequently, a structure of not less than 10 Work Groups (WG), **defined by fields of expertise**, deals with standard and best practices in epilepsy care. Systematic interaction between those WGs ensures a multidisciplinary approach. The comprehensive actions provided by experts involved in the "*standard and best practices*" WGs are in parallel shared with those involved in a set of "transversal" WGs. So, another 10 transversal WGs focus on *healthcare policies, data collection and sharing, innovative research, knowledge generation and guidelines, training of both medical doctors and nurses*, etc.

The aim being to identify epilepsy care needs and propose state-of-the-art diagnosis and treatment practices, at both a national and an EU level.

Indeed, an offer of high-quality epilepsy care in proximity to the patient's place of work and domiciliation highly depends upon the quality of the physical and clinical examination of each individual patient, the quality of the investigations performed. A constant amelioration of national/regional healthcare practices, improving accessibility to targeted diagnostics and treatments, is a prerequisite for optimal coordination at an EU level, the main mission of the ERNs as networks of experts across the EU.

In parallel, development of a close and sustainable partnership with patient advocates (ePAG) for a better-structured healthcare system, accessible to all European citizens, independently of their origine is its priority.

Funding for the management of the network is provided by a European Commission multi-beneficiary grant, under the EU4Health program. The current grant covers the period of October 2023–September 2027. It is managed by the Children's University Hospital San Juan de Dios, Barcelona, Spain (Coordinating HCP) and the University Hospitals of Leuven, Belgium (HCP in charge of the Registry) and Salzburg, Austria (in charge of Guidelines, Education & Training). The accredited medical teams do not receive direct funding by the Commission. They depend on their respective national healthcare systems.

With respect to the Directive of the European Commission, both EpiCARE as a network of expert centres and separately its accredited medical teams are subject to regular evaluation procedures from an Independent Evaluation Body. Membership accreditation can be retrieved.

All transversal actions developed by EpiCARE, particularly those related to cost effective healthcare policies, sharing of best practices, educational and training activities, guidelines, and clinical tools are systematically developed in very close partnership with the scientific societies in the field (ILAE-Europe; EAN; EPNS) and the patient advocates lay association (IBE). EpiCARE also contributes to the development of inter-ERNs transversal panels of experts, particularly with the ERNs that are also caring for disorders with neurological and neurodevelopmental disabilities. Individual experts from many of the EpiCARE members and beyond are progressively joining the different Working Groups, a unique forum for knowledge generation and sharing.

This booklet provides useful information about EpiCARE activities and how you can contribute to their further development by sharing your competencies and expertise.

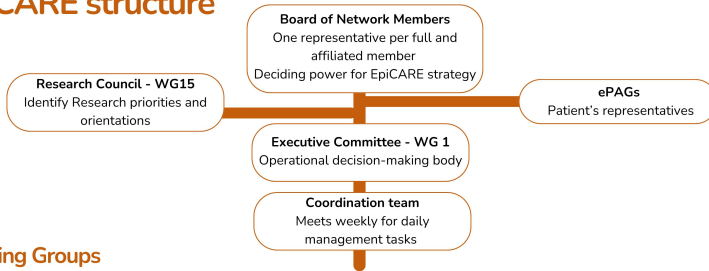
## Where is EpiCARE?



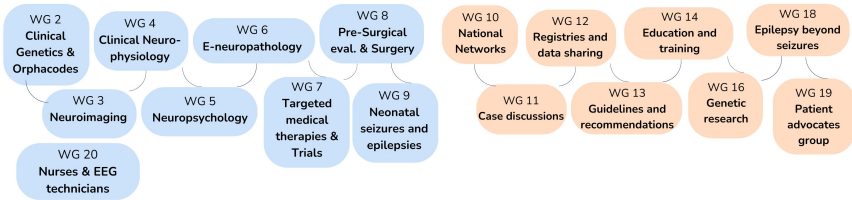
The figure below illustrates the current operational structure of EpiCARE. A detailed description of the WGs missions follow. The WGs welcome contributions from all experts working in the European region.

# Best practices, healthcare policies and innovative research

## EpiCARE structure



## Working Groups





# Executive Committee

ERN EpiCARE Coordinator : Alexis Arzimanoglou, Spain

Carmen Barba, Italy	Morten Ingvar Lossius, Norway
Sandor Beniczky, Denmark	Maša Malenica, Croatia
Irena Bibic, Croatia (ePAG)	Petr Marusič, Czech Republic
Ingmar Blümcke, Germany	Rima Nabbout, France
Isabella Brambilla, Italy, (ePAG chair)	Ronit Pressler, UK
Kees Braun, The Netherlands	Guido Rubboli, Denmark
Helen Cross, UK	Philippe Ryvlin, Switzerland
Christoph Helmstaedter, Germany	Nicola Specchio, Italy
Reetta Kalviainen, Finland	Rainer Surges, Germany
Kotulska Kasia, Poland	Eugen Trinko, Austria
Lieven Lagae, Belgium	Federico Vigevano, Italy

The ExCo is the operational decision-making body of EpiCARE composed by established clinicians or researchers with a strong track record in the field of epileptology. It reports to the Annual Convention and at the meetings of the representatives of the 50, full and affiliated, members of EpiCARE (Board of Members).

The ExCo is composed of the following voting members:

- o The Coordinator, directly elected by the Board of Members.
- o The Chair and co-chair of the EpiCARE Research Council.
- o The Chairs of the EpiCARE core Working Groups (as per action plan).
- o Two patient advocate (ePAG) representatives.

One representative of each of the following scientific societies is invited to participate, as non-voting member: European Executive Committee of the International League Against Epilepsy (ILAE-EUROPE); the International Bureau for Epilepsy (IBE); the European Academy of Neurology (EAN); and the European Paediatric Neurology Society (EPNS).

At the discretion of the Coordinator, of the Research Council and/or WG chairs, other experts, actively involved in EpiCARE actions, can be invited to contribute as non-voting participants.



## Clinical Genetics & Orphacodes

*The identification of aetiological groups throughout the EU will provide appropriate genetic, metabolic and immune testing to a wider population.*

Increasingly genetic, autoimmune and metabolic epilepsies are being recognized although few characteristic epilepsy phenotypes have been identified (i.e. PCDH19, SCN1A, NMDA encephalitis, GLUT1 deficiency) that permit prediction of which aetiology is likely involved. Progressive refinement of the phenotype will reduce the number of patients who require molecular genetics, for diagnostic purposes (with consequent financial impact, particularly for patients with poor social coverage).

Neural autoantibody testing and metabolic testing can also be targeted more. Refining phenotypes requires that specific features (seizure, EEG, MRI characteristics, cognitive profile, psychiatric, movement and other possible comorbidities,) are identified accurately by physicians with appropriate expertise. Knowledge of these additional symptoms and their prediction may permit actions to reduce their impact.

For given conditions, few experts have devoted time on the identification of the phenotype. The WG is open to clinicians and geneticists who may contribute to this phenotypic refinement across age groups, share expertise when discussing complex cases and provide genetic counselling.

We also work for a homogeneous, optimal, ethical and cost- benefit approaches of genetic testing within the EU and for a regular update of the Orphacodes and corresponding summaries.

### Chair



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Enfants Malades  
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### Co-chair



Rikke Moller  
Danish Epilepsy Centre,  
Filadelfia  
Dianalund, Denmark

# 3

## Neuroimaging

*Neuroimaging investigations are fundamental in the diagnosis of patients with epilepsy, in identification of aetiology and in selected cases for surgical planning.*

In recent years, there have been tremendous advances in the availability and acquisition of structural MRI, functional MRI, PET and SPECT imaging. Furthermore, advanced post-processing methods and machine-learning algorithms have been applied to neuroimaging data in patients with epilepsy.

This working group aims to promote harmonisation of best practices in neuroimaging evaluation of rare and complex epilepsies to enable and ensure state-of-the-art care across EpiCARE centres and beyond.

We have a group of radiologists and neuroimaging post-processing experts from across the EpiCARE network. We organise EpiCARE webinars on neuroimaging in rare and complex epilepsies as well as education interactive workshops on neuroimaging post-processing and radiological interpretation. These workshops aim to improve the clinical and technical neuroimaging skills of EU professionals involved in the management of rare and complex epilepsies.

They aim to facilitate the use of state-of-the-art neuroimaging post-processing tools as research adjuncts for surgical evaluation of epilepsy patients as well as facilitating the participation of EU centres in multi-centre research projects, such as ENIGMA-Epilepsy (<https://enigma.ini.usc.edu/ongoing/enigma-epilepsy/>) and the MELD Project (<https://meldproject.github.io>).

### Chair



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Motol University Hospital  
Prague, Czech Republic

### Co-chair



Sophie Adler  
UCL Great Ormond Street  
Institute of Child Health  
London, UK

# 4

## Neurophysiology

*Experience and expertise in clinical neurophysiology are required to recognise the advantage of accurate recording and interpretation.*

Clinical Neurophysiology methods, especially EEG, provide valuable information for diagnosing the epilepsies, with specific patterns identified in many diseases requiring expert interpretation. We are focusing on practices and development of tools that integrate recent advances into EpiCARE centres and National Reference Networks.

### **PROMAESIS**

This is the acronym for Prospective Multicenter-study on Automated EEG Source Imaging in epilepsy Surgery (NCT04218812). The data collection phase (n=392) has been completed, and all EEGs have been analysed (Epilog & BESA). The pre-surgical clinical data have been collected and currently we are waiting for the CRFs on the 1-year postoperative outcomes. The postoperative data are currently streaming in. One side-project on the automated / semi-automated detection of IEDs and the effect of spatial sampling has been published in July 2022 (Heers et al., Epilepsia 2022).

### **SCORE-EpiCARE**

Since the last reporting, we have published a paper on seizure-duration, based on the large SCORE dataset (Meritam et al., Epilepsia 2023). An inter-rater agreement on periodic and rhythmic EEG patterns using SCORE is currently ongoing in several EpiCARE Centres. The inter-rater agreement is intended as a means of standardizing the recognition of these difficult-to-interpret patterns and improving the management of these challenging entities. The working group participated in regular online meetings and an increased knowledge of the SCORE program has been spread among EpiCARE centres. Nearly 300 EEGs have been collected, which will allow determining inter-rater agreement with higher numbers than previous studies in the literature, using a highly standardized program for the detection and classification of EEGs (SCORE). Future developments of the project have been discussed in the working group, including the possibility to consider the EEG material collected for educational purposes - to be developed and disseminated through EpiCARE.

### **Chair**



Sandor Beniczky  
Danish Epilepsy Center  
Aarhus University  
Denmark

### **Co-chair**



Elena Tartara  
IRCCS Fondazione Istituto  
Neurologico Nazionale Mondino  
Pavia, Italy

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# Neuropsychology

*Epilepsy is more than having seizures. Behavioral and cognitive comorbidities are very common and sometimes affect everyday life and functioning more than seizures.*

Our WG aims to improve the assessment of cognitive and behavioural comorbidities at disease onset and along the disease course (e.g., treatment-related changes, the impact of epileptic dysfunction, developmental hindrance, mental decline, etc.). Neuropsychology can also serve as a differential diagnostic indicator of epilepsy subtypes and syndromes when related to imaging, electrophysiology, pathology, and genetics data. It allows monitoring of disease dynamics and can be used for outcome and quality control of treatments.

Composed of both adult and paediatric neuropsychologists, we focus on work in Special Interest Groups, open to those interested to lead them or contribute focusing between others, on: Patient-centred outcome measures; uniform reporting and neuropsychological data collection; EEG-logged assessment of cognition; Psychosocial consequences of late-onset epilepsies; Epilepsy with continuous spike-wave during slow-wave sleep; Right cerebral hemisphere and Autism Spectrum Disorders; Cognitive outcome of preschool children after epilepsy surgery; Transition from childhood to adulthood.

We lead regular sessions of case presentations to share knowledge on best practices in neuropsychological evaluation and contribute to surgical and non-surgical case discussions. We closely collaborate with WG 18 on challenges “beyond seizures”.

## Chair



Christoph Helmstaedter  
University Hospital Bonn  
Germany

## Co-chairs



Andrea Palacio  
Hospital Sant Joan de Déu  
Barcelona, Spain

## Neuropathology

*Microscopic tissue diagnosis of human brain disorders remains the gold standard in modern medicine. Yet, histopathology training in epileptic disorders is difficult to obtain in many European countries.*

EpiCARE offers a comprehensive neuropathology service for all of their members. Currently, our working group mainly addresses three activities:

1) The European Epilepsy Brain Bank with a collection of more than 10.000 histopathology diagnoses obtained from epilepsy surgery. This unprecedented dataset is further used for benchmark EpiCARE projects on disease aetiologies, outcome and pathomechanisms.

2) We offer a diagnostic histopathology consultation for surgical brain samples obtained from epilepsy surgery using standardized protocols. The results are available through the CPMS platform. Formalin- fixed and paraffin- embedded tissue specimens should be sent to the neuropathology laboratory in Erlangen, Germany or can be shared online as fully digitized slides.

3) Finally, we offer an interactive, online post-surgical patient management conferences to discuss surgical brain specimens from various European epilepsy surgery centres.

Our efforts will help guide histopathologists in Europe to harmonize their diagnosis and diagnostic tools according to current medical standards, i.e. ILAE and WHO classification schemes, and help to deliver best medical care for our patients with difficult-to-treat rare and complex epilepsies. This work is likely to also influence the histopathology work-up outside Europe.

### Chair



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## 7

## Targeted therapies & Clinical trials

*For many of the rare and complex epilepsies, approved and evidence-based treatments do not exist. Thus, there is an urgent need to support high quality evidence of clinical studies and to identify and develop novel treatments targeting specific aetiologies.*

Recognition of the epilepsies as a group of rare diseases with known aetiologies give us insight as to the underlying mechanisms involved in both development of seizure-generating networks, as well as comorbidities such as cognitive, physical, emotional and behavioural disturbances.

To improve study designs and choice of relevant interventions, there is a need to collect standardized data on outcomes associated with specific treatments such as anti-seizure medications, repurposed drugs targeting underlying mechanisms, disease-modifying treatments (including immunosuppression, treatments targeting protein and gene expression), and non-pharmacological treatments (such as diets, neurostimulation, and surgical therapies) or interventions (cognitive, behavioral and physical therapies) in people with rare and complex epilepsy.

To foster advancements, special interest groups (SIG) for specific epilepsies (e.g. autoimmune epilepsies, tuberous sclerosis, etc), and with focus in specific aspects of trial design (e.g. n-of 1- methodology, use of PCOMs etc.) were established to identify the particular needs of an entity to enable conduction and ultimately performance of clinical trials.

The goals of this working group are to support and review initiatives in identifying unmet needs, study development and designs, provide expertise by contributing to activities of the European Consortium for Epilepsy Trials (ECET), disseminate these initiatives and study results. We also contribute to educational initiatives to improve the knowledge of novel trial designs, analysis, and outcome measures.

### Chair



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### Consultant

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Casimiro Mondino, Italy



Valentina De Giorgis  
Istituto Mondino  
Pavia, Italy

## Pre-surgical evaluations & surgery

*Surgery is now long established as standard management of carefully selected patients with focal epilepsy. There are many aspects, however, that can be particularly challenging and deserve special consideration in the evaluation for surgery and planning of surgical strategy.*

Epilepsy-surgery in appropriately evaluated patients is seen to be effective over a wide age range, and over a spectrum of clinical presentations and pathologies. Furthermore, the likely impact that can result from early evaluation and surgery with resulting seizure control suggest that patients, especially children, should be referred and assessed early in their clinical course.

The members of this WG contribute to:

- Regular e-care visioconferences, led by experts, to discuss best practices in pre-surgical evaluation; epilepsy-surgery indications; results of surgery, both successes and failures. The case discussions are also of high educational value and are open to all EpiCARE members.
- IT platform: it allowed each EpiCARE centre to get access and use sophisticated neuroimaging and EEG postprocessing tools (e.g. Curry8).
- Epilepsy Surgery REDCap eCRF: This comprehensive eCRF aimed at collecting all relevant data from patients undergoing presurgical evaluation and epilepsy surgery. Its regular use by the centres will allow collection of comparable data on the natural history of focal epilepsies per aetiology, both retrospectively and prospectively.
- The CogniEEG project: EpiCARE centres are core members of the CogniEEG project which aims at leveraging cognitive research performed in patients with epilepsy undergoing intracerebral EEG recordings (iEEG).

It is expected that all data collected through the above activities will progressively populate the EpiCARE Registry, thus facilitating the design and performance of academic studies related to epilepsy-surgery needs and outcomes.

Members of the WG are active participants to the just launched process for Guidelines on pre-surgical evaluation; epilepsy-surgery; and invasive neuromodulation.

### Chair



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Universitaire Vaudois  
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### Co-chair



Sylvain Rheims  
University Hospitals of  
Lyon Lyon, France

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## Neonatal seizures

*Neonatal seizures are associated with poor outcome, but their management is challenging due to difficulties in diagnosis and treatment.*

In contrast to seizures in older children, EEG monitoring is essential to accurately detect ongoing seizures in neonates given the high frequency of electrographic- only seizures and their variable clinical expression. EEG monitoring needs to be available 24 hours a day in neonatal intensive care units for optimal surveillance, which is challenging. Many units in Europe therefore use amplitude integrated EEG (aEEG), which is less accurate in detecting seizures. Accurate seizure detection is essential for appropriate and prompt treatment and for randomised trials of new treatments.

Our WG began work on a protocol for neonatal EEG monitoring and reviewed all the published protocols at the same time as the Italian Neonatal Seizure Collaborative Network (INNESCO) worked, with contribution from EpiCARE members, on a comprehensive protocol (Dilena et al 2021), which was adopted by EpiCARE. The ILAE have recently published guidelines and consensus-based recommendations for the treatment of seizures in the neonate, which have been developed with members of the EpiCARE neonatal WG. The group also:

- developed a free neonatal EEG eLearning module to help centres across Europe get EEG monitoring up and running, to recognise the common neonatal seizures types and to distinguish them from common artefacts encountered in the NICU.
- working on the development of a Neonatal Seizures Registry with a multicentre open cohort design that includes acute symptomatic seizures and neonatal-onset epilepsies, the results of diagnostic biochemical, MRI and genetic tests, together with the aetiologies. In the next phase, we will assess if this real-world data can be used to promote collaborative research across Europe.

We will also assess neonatal EEG and seizure AI algorithms and develop guidelines for their use in neonatal EEG monitoring but also in clinical trials of new treatments.

### Chair



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### Co-chairs



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Infant Research Centre  
Cork, Ireland



Carmen Fons  
Hospital Sant Joan de Déu  
Barcelona, Spain



# 10

## National Networks

*Strengthening the links between EpiCARE and existing, or under development, national epilepsy networks and pathways for optimal epilepsy care is one of our priorities.*

The governance structure of ERN EpiCARE that facilitates, pooling and sharing knowledge, fostering research and innovation, as well as the discussion on rare or low prevalence complex epilepsies is now in place. To reap all benefits for patients, effective mechanisms to connect EpiCARE medical teams with national health systems need to be developed.

The National Networks WG aim is to reinforce building national/regional epilepsy care pathways to ensure timely referral to the right level of care, systematic follow-up, awareness of treatment options and self-care, good communication between the different actors and flexible consultation possibilities including national case discussions before referring the case to the ERN-level discussions. National networks need also to include peer support to reinforce care and a service plan, where appropriate.

Our upcoming tasks are:

- to complete the mapping of the current situation of national epilepsy care pathways in EU countries and to provide a thorough analysis of the mapped pathways to identify strengths, weaknesses, gaps, and opportunities for building better epilepsy care pathways;
- to harmonize minimum requirements for level 3 and 4 epilepsy centres within the EU; via systematic literature review and Delphi process among EpiCARE ERN members;
- to reinforce national and regional activities to link EpiCARE ERN to the national health care systems serving epilepsy patients.

Our actions also take into consideration the ILAE-IBE recommendations for an integrated approach to «epilepsy and other neurological disorders» (WHO iGAP) and contribute to actions taken at the level of the EU member states, within the frame of the Direct-Action grant, **JARDIN**, funded by the Commission.

### Chair



Reetta Kalviainen  
Kuopio University  
Hospital Finland

### Co-chair



Katarzyna Kotulska - Józwiak  
Children's Memorial Health  
Institute Warsaw, Poland

*Case discussions are an integral part of all ERNs and are in line with the European Commission's Directive. EpiCARE undertakes regular case discussions in specialised areas of the rare and complex epilepsy field, including surgical and non-surgical cases, neuropsychology and neuropathology.*

Case discussions utilise the Clinical Patient Management System (CPMS) which is an online secure and encrypted platform, provided by the EU. It allows for free-flowing discussion amongst experts, enabling complex patient cases to have multi expert input and therefore optimise the care and treatment of rare and complex epilepsy patients. There are two ways in which cases can be discussed and these are in an online meeting area within the CPMS platform or via written contributions, both avenues allow for detailed examination of each case and feedback provision.

Other clinical cases are discussed at face-to-face meetings, organized by EpiCARE members (ex. U-Task; Stereo-EEG course; EPIPED and Tagliacozzo courses, endorsed by ILAE-Europe).

The members of this WG are working to increase attendance and participation in these case discussions and to highlight areas within the rare and complex epilepsy field that would benefit from these multi-disciplinary discussions. Currently we have at least 3 regular sessions per month: for both potentially surgical cases and/or surgical successes or failures, as well as for non-surgical cases. We also support sessions organized by other EpiCARE WGs bringing together experts in neuropathology, neuropsychology, neuroimaging and genetics.

Detailed information on how an EpiCARE member can submit a complex case for discussion or how to join a discussion as an expert or simply for educational purposes are provided on our website: <https://epi-care.eu/case-discussions-epicare/>. If you are interested to join one of our expert panels and be informed about sessions related to your field of expertise you can inform the EpiCARE Helpdesk: [helpdesk@epi-care.eu](mailto:helpdesk@epi-care.eu).

### Chair



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Bambino Gesù  
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### Co-chair



Tobias Baumgartner  
University Hospital Bonn  
Germany

# 12

## Registry

*Developing a Registry for rare and complex epilepsies is a very dynamic process, with continuous challenges and needs to update and refine the content. We are confident that its creation will offer the EU epilepsy community a unique tool to support both clinical practice and research.*

This group includes epilepsy specialists, as well as patient representatives and IT specialists (a subcontracted company, BIOMERIS).

At present, the Registry contains the EU defined Common Data Elements (eg demographics, ORPHANET codes) and specific epilepsy items, focusing on aetiology. The EpiCARE Registry is designed to be user-friendly and requests information almost exclusively related to the aetiological category, as per the ILAE classification: genetic, structural, immune, inflammatory, metabolic and unknown background parameters. It is being implemented as a local tool in all EpiCARE centres - an obligation for all EpiCARE members, full or affiliated - on a dedicated REDCap platform. The Registry template content can be offered to all other epilepsy centres wishing to homogenize the collection of essential data in their respective Institutions. Pseudonymisation with the SPIDER software will soon allow to eventually congregate all EpiCARE local registries within one central server. At that point dedicated clinical research questions can be supported with our registry data. It will soon be possible to link to our main Registry, sub-registries, or more detailed databases, funded by academic research projects and developed for specific projects (eg. Neuropsychology; neonatal epilepsies; TuberousSclerosisComplex;...)

We are fully aware of the difficulties encountered by the medical teams, usually due to legal issues and/or lack of support from their respective Institutions. Indeed, many hospital administrations interpret the creation of an across the EU Registry for Rare Diseases as a research project per se, which is definitely not the case. The issue becomes even more complex, due to the diversity and autonomy of national health systems when the discussions concern data sharing. Our WG will contribute to the procedures to be initiated within Direct Action grant to member states, JARDIN, aiming at the development of recommendations for national RD data governance models that will be interoperable with the ERN registries and CPMS.

### Chair



Lieven Lagae  
University Hospital  
Gasthuisberg KU Leuven  
Belgium



**EpiCARE** Registry

an operational registry for all rare and complex Epilepsies

*The development of clinical guidelines and recommendations is essential for the implementation of best practices in epilepsy care.*

The WG on Guidelines and Recommendations involves several EpiCARE members from different countries and is organized in topic-related Task Forces.

Its objectives are: quality assessment of existing guidelines for rare and complex epilepsies; identification of the areas where development of epilepsy guidelines are required; development of new guidelines when needed; evaluation of the dissemination and implementation of guidelines across Europe.

All developments follow the rules of the GRADE Methodology (Grading of Recommendations Assessment, Development and Evaluation), which uses the best available evidence along with expert opinion and patient representatives to develop explicit criteria to guide clinical care. To ensure contribution from all available experts a Memorandum of Understanding was signed between EpiCARE, the European-based scientific societies (EAN and EPNS) and the ILAE. Following a large survey to identify areas where development of guidelines is needed, the following are already in the pipeline:

- o Pharmacological and non-pharmacological interventions in the treatment of :
  - Lennox-Gastaut syndrome
  - infantile spasms syndrome
  - Dravet Syndrome
- o Pharmacological treatment of status epilepticus in adults
- o Guidelines for presurgical evaluation and surgical treatment of patients with

complex and drug resistant epilepsies, divided into 3 sections: pre-surgical evaluation; epilepsy surgery proper; invasive neuromodulation

Under the leadership of the EpiCARE Salzburg centre the WG is composed by discipline/content experts, a neurologist-methodologist (Dr Teia Kobulashvili) and, when needed, statisticians and information specialists. We also work in close collaboration with the Cochrane epilepsy group.

EpiCARE members wishing to contribute to the guidelines work can contact the Project Manager of the WG, Martin Geroldinger: [martin.geroldinger@epi-care.eu](mailto:martin.geroldinger@epi-care.eu) or the EpiCARE Helpdesk: [helpdesk@epi-care.eu](mailto:helpdesk@epi-care.eu).

### Chair



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# 14

## Education & Training

*Our main goal is to develop educational practices favouring dissemination of highly specialized knowledge and expertise within the members of the ERN and beyond, and to operationalize complementarity. We aim to adapt the educational orientations recommended by the ILAE Roadmap for education to the needs of experts working in Europe.*

With the generous contribution of experts in the corresponding fields, jointly with ePAGs, we continuously develop a program of [educational webinars](#). Together with the e-learning modules developed in partnership with the ILAE, they offer comprehensive state-of-the-art reviews, accessible to all and free of charge. At first presentation, all our webinars also offer a “meet the expert” opportunity during a live Q&A part. Collected evaluation surveys following educational webinars and their outcomes are used as a tool for reflection and improvement of future webinars and other educational materials. The webinars are available on our website and present a library of knowledge that can also be used for training purposes at all medical departments caring for the epilepsies.

Members of ERN EpiCARE, in close collaboration with ePAGs, also regularly develop and disseminate leaflets for caregivers and patients with rare epilepsies and comprehensive patient’s journeys descriptions. Training in clinical epileptology and related disciplines requires the physical presence of young clinicians and researchers at epilepsy reference centres. All ERN EpiCARE members and collaborating partners offer training possibilities and can be directly contacted by those interested. We also support next-generation experts wishing to present the results of their studies at epilepsy congresses or at the annual Rome workshop, endorsed by EpiCARE and ILAE-Europe. A mentor-mentee program was also launched in 2024.

ERN EpiCARE is one of the 3 pilot ERNs, missioned to contribute to the future development of an ERN ACADEMY and an active member of the ERNs Knowledge Generation WG, focusing upon the development of a joint strategy of the ERNs for training and education to overcome the gap between the increasing awareness on rare and complex diseases and the lack of a specific training in the medical curricula.

### Chair



Maša Malenica  
University Hospital Centre  
sestre milosrdnice  
Zagreb, Croatia

### Co-chair



Ronit Pressler  
Great Ormond Street  
Hospital  
London, UK

*Fostering research and innovation is, according to the EU Directive for the creation of the ERNs, one of their main missions.*

The ERNs, although funded by the EU4Health program, are not research projects per se and cannot directly fund research and innovation initiatives. But they offer unique opportunities to medical teams who wish to develop, lead, and submit grant applications for research projects or just be partners in a funded project. This opportunity is offered to all medical teams, independently of their status (full or affiliated member, collaborating partner). To foster research, EpiCARE developed several Working Groups covering all aspects of epilepsy care. Every effort is also made by our patient advocates group to be represented in all WGs and contribute a better understanding of patient needs and expected outcomes.

To ensure an optimal coordination to foster research and innovation, EpiCARE funds a Project Manager competent in epilepsy research, Sébile Tchaicha ([sebile.tchaicha@epi-care.eu](mailto:sebile.tchaicha@epi-care.eu)). The Research Council aims to stimulate multicentre studies; optimize ethical, methodological, and statistical approaches; improve and optimize trial feasibility and reliability. Between other missions, the members of the Research Council also contribute and/or follow the activities of projects such as the [EJP RD](#), [SOLVE-RD](#), [ERICA](#), [EBRAINS](#), [Human Brain Project](#), [EpiCLUSTER](#) and others.

Upon request, the Research Council supports EpiCARE members wishing to evaluate a research project before submission, provides advice for collaboration with other medical teams, members or not of the network. It can also provide letters of support by the network, particularly by reinforcing the feasibility information for a given project (use of the Registry; proposal for EpiCARE partners etc.). The council shares with all, 3 times per year, a newsletter including updated information on HORIZON and other research calls.

**Members are:** Alexis Arzimanoglou (Spain), Sandor Beniczky (Denmark), Ingmar Blümcke (Germany), Philippe Ryvlin (Switzerland), Renzo Guerrini (Italy), Rainer Surges (Germany), Eugen Trinkla (Austria), Lieven Lagae (Belgium), and Rima Nabbout (France).

## Chair



Helen Cross  
Great Ormond Street Hospital  
London, UK

## Co-chair



Kees Braun  
University Medical Center  
Utrecht  
The Netherlands

# 16

## Genetic Research

*Genetic research in the field of epilepsies is confronted with an extremely large number of new genes, for which the clinical spectrum and/or natural history is often barely known; usually, the number of patients published is limited to a handful, their recruitment may be strongly biased towards a few clinical features, and their clinical description is often limited.*

In a joint effort to promote genetic research, members and non-members of EpiCARE, conveyed into this WG the knowledge and opportunities that have derived by their participation as active members to major concluded and existing EU research networks on epilepsy research in genetics and rare epileptic encephalopathies. To boost the genetic research activities we contributed to the development of a [web-platform for patients' matchmaking](#), interoperable with other discovery services, based on the RD-NEXUS tool, and provided by the European Joint Project in Rare Disease (EJPRD) to support the wider ERN community. Furthermore, a dedicated webpage offers the possibility to all medical teams to share opportunities of collaborative calls, recruit cohorts of patient carrying rare variants in genes without a well-defined phenotypic spectrum, where single-centre studies would not yield significant series.

ERN-EpiCARE has also joined, as an associated ERN, Solve-RD, a Horizon2020-funded project, dedicated to "solve the unsolved rare diseases". This will permit the re-analysis of unsolved exomes and genomes of patients with rare developmental and epileptic encephalopathies (DEE) or other rare epilepsy syndromes.

Members of the WG regularly contribute to educational webinars focusing on genetic epilepsies, organized by the Education and Training WG. The presentations systematically combine a clinician and a geneticist. When appropriate a patient advocate is also involved. A "training in genetics of the epilepsies" workshop is under preparation.

### Chair



Renzo Guerrini  
Azienda Ospedaliero-  
Universitaria A. Meyer  
Florence, Italy

### Co-chair



Gaetan Lesca  
University Hospital of Lyon  
(HCL)  
France

*Dissemination and communication is essential ensure maximal impact of the network's activity, projects and events.*

Dissemination pursues 6 main objectives :

- Continuous, detailed and transparent reporting on ERN EpiCARE to give visibility, raise awareness of the project and engage relevant stakeholders.
- Raise interest about rare and complex epilepsies, the ERN ecosystem and ERN EpiCARE. Strengthening the presence of it.
- Empower those affected by rare epilepsies and their families to actively participate in EpiCARE activities and missions, learn about their condition and ask for support. Build a patient-centred communication.
- Use all available means of dissemination to ensure maximum impact of all activities and results.
- Ensure good internal communication to support practitioners and foster effective exchanges and collaborations.
- Strengthen the integration of ERN EpiCARE into national healthcare systems.

The current dissemination plan is based on the past 7 years' experience. Correct communication planning in EpiCARE will help to improve outreach to external audiences and positioning, and it will improve the feeling of relevance among members. The role of its active members is to propose and advise on actions at EU level, check before dissemination all material with scientific content, promote the webinar and issue Newsletters.

The dissemination efforts cover different target groups, using various tools: the EpiCARE website, social media (LinkedIn, Twitter and Facebook), regular mailings (contact list of more than 6000 e-mails) and the intranet (reserved to members). EpiCARE is also present at all major congresses in the field: ILAE-Europe; EAN; EPNS.



Laura Roig

EpiCARE management team  
Communication Manager

Hospital Sant Joan de Déu (HSJD), Spain



*Psychosocial issues, quality of life, patient perspectives (PROMS), sexuality, ASM adherence and many others, are essential to a comprehensive care of the epilepsies, independently of age and seizure severity.*

The main aim of WG18 is to work on issues related to global epilepsy care. Such as:

- Comorbidities in general;
- Psychiatric, behavioural and emotional regulation issues;
- Sexual dysfunction;
- ASM adherence-issues;
- Lifestyle and seizure-precipitating factors;
- HRQOL-issues;
- Patient reported outcomes (PROMS).
- Social integration issues

Following a survey on *“Use of screening tools to assess comorbidities and adverse events in patients with epilepsy. A European Reference Network for Rare and Complex Epilepsies (EpiCARE) survey”* (Henning et al. 2022), WG18 was initiated by a group of adult neurologists from Norway (M. Lossius – Chair), K. Åshild Alfstad, O.J. Henning), Denmark (G. Rubboli), Finland (R. Kälviäinen, J. Peltola) and Germany (Ch. Helmstaedter, H. Hamer, A. Schulze-Bonhage, B. Steinhoff). After the face-to-face 4th “In search of lost time” workshop, held in Rome (December 2023), the WG18 expanded to include child neurologists. They are expected to contribute to all challenges mentioned above and focus on issues related to intellectual disabilities, led by S. Jozwiak (Poland).

Very recently a Special Interest Group (SIG) **on Transition** was created, lead by V. De Giorgis (Italy) and M. Malenica (Croatia). A survey was launched, aiming to have a “photo” of the practices in EpiCARE centres and on how our members deal with transition from childhood to adolescence and adulthood of patients with:

- Epileptic & Developmental Encephalopathies;
- Drug-resistant Juvenile Myoclonic Epilepsy or focal idiopathic/LKS/CSWSS;
- Drug-resistant Focal Structural Epilepsies that could not benefit from surgery (following pre-surgical evaluation) or already operated on without a full control of seizures or persisting comorbidities.



## Chair

Morten Lossius  
National centre for  
epilepsy Oslo, Norway



## Co-chair

Sergiusz Jozwiak  
Children’s Memorial Health <sup>25</sup>  
Institute (Warsaw, Poland)

*Partnership between medical experts in rare and complex epilepsies with families and patients suffering from them is an important mission of EpiCARE.*

European Patients Advocates (ePAGs) for epilepsy care are an independent body of patient representatives, who are either leaders in rare and complex epilepsy patient organisations from across Europe, or patients themselves. The group currently consists of 15 members (<https://epi-care.eu/epicare-patient-representatives/>), from various European countries representing different conditions. They are the voice of patients for EpiCARE, produce deliverables to support patients and their families, facilitate communication between patients and healthcare professionals.

The patient empowerment working groups main mission is to better coordinate interactions between the patient advocates group and the EpiCARE medical teams by:

- Reinforcing the links between existing and under development federations and associations of patients with rare and/or complex epilepsies, the EU chapters of the International Bureau for Epilepsy (IBE) and the ERN EpiCARE community.
- Supporting the patient associations to better defend the need for national and EU plans for epilepsy care. This is of particular importance in the coming years - in a joint effort with EpiCARE and the European chapters of the ILAE and the IBE - aiming to adapt and implement in Europe the Intersectoral Global Action plan (iGAP) on «epilepsy and other neurological disorders (2022-2031) adopted by the WHO Assembly.
- Incorporating the voice of patients from the different EpiCARE WGs and collaborating to develop information, dissemination, guidelines, and support to research projects.
- Pursue, in collaboration with EpiCARE experts, with projects that increase disease knowledge for patients, families and non-expert treating physicians such as: Webinars, definition of Patients Journeys, Leaflets, and publications in scientific journals.

## Chair



Isabella Brambilla  
Patient representative  
ePAG chair  
Dravet Onlus Italy

## Co-chair



Alexis Arzimanoglou  
Hospital Sant Joan de Déu  
Spain

## Epilepsy Nurses

*Partnership between medical experts in rare and complex epilepsies with families and patients suffering from them is an important mission of EpiCARE.*

Nurses and EEG technicians working at epilepsy monitoring units and/or for Neurophysiology, Neurology and Child Neurology Dpts. that care for patients with epilepsy are an essential partner of a multi-disciplinary team.

They are the ones who have an everyday SPATA5 in Rome second roundday contact with the patients and their families, perform the EEG (one of the most essential diagnostic tools), provide counselling on how to take anti-seizure medication or follow a ketogenic diet, administer rescue medications, test the patients during a seizure to better identify localization signs but also protect them from accidents, etc.

The WG was made a part of the ERN EpiCARE programme in late 2022. Its creation results from the successful exchange program (2020-22), funded by the management budget of EpiCARE, supporting nurses and EEG technicians working at EpiCARE centres to visit other monitoring units. It was launched during a workshop held in Utrecht (06/23) at the EpiCaRE annual meeting, involving nurses and VEEG technicians working in the field of epilepsy care and epilepsy monitoring units.

The upcoming tasks are:

- Undertake a coordinated literature review of monitoring practices and the differences in units/centres in the EU.
- Compare and contrast monitoring practice guidelines from ERN EpiCare centres.
- Prepare a manuscript (for submission to an appropriate journal) with findings and recommendations.
- Produce a manuscript on the reasonings behind the launch of this WG and its benefits and aims.
- Assess the learning and practice needs of epilepsy nurses and EEG technicians working in Europe;
- Contribute to the development, and adapt to European standards and needs, of an education curriculum for epilepsy nurses and EEG technicians.
- Learn from each other and improve patient care.

The WG works in close collaboration with the [Nursing section of the ILAE](#).



Nicola Lawrence  
EpiCARE management team  
CPMS, Patient Advocates and Nurses Project  
Great Ormond Street Hospital, London, UK

# EpiCARE Members

- Austria, Christian Doppler University Hospital, Paracelsus Medical University
- Austria, Medical University of Vienna, Center for Pediatric Epilepsy / Dpt. of Pediatrics
- Belgium, Cliniques Universitaires Saint-Luc (Brussels Rare and Complex Epilepsies Consortium BRACE)
- Belgium, Hôpital Erasme (Brussels Rare and Complex Epilepsies Consortium BRACE)
- Belgium, Hôpital Universitaire des enfants Reine Fabiol (Brussels Rare and Complex Epilepsies Consortium BRACE)
- Belgium, Centre Neurologique William Lennox (Brussels Rare and Complex Epilepsies Consortium BRACE)
- Belgium, Institut de Pathologie Génétique (Brussels Rare and Complex Epilepsies Consortium BRACE)
- Belgium, University Hospital Gasthuisberg KU-Leuven
- Croatia, University Hospital Centre Zagreb, School of Medicine -Department of Neurology
- Croatia, University Hospital Centre Sestre Milosrdnice - Klinički bolnički centar Sestre milosrdnice
- Cyprus, Cyprus Institute of Neurology and Genetics -CFMDR (CING)
- Czech Republic, St. Anne's University Hospital and University Hospital Brno, Brno Epilepsy Center
- Czech Republic, Motol University Hospital (FNM)
- Denmark, Rigshospitalet-Blegdamsvej and Danish Epilepsy Center Filadelfia, Epilepsiklinikken
- Denmark, Aarhus Universitets Hospital
- Estonia, Tallinn Children's Hospital
- Estonia, Tartu University Hospital
- Finland, Kuopio University Hospital, Pohjois-Savon Sairaanhoidopiiri (KUH)
- Finland, Hospital District of Helsinki and Uusimaa, HUS Helsinki University Hospital (Oulu ERNEpi Consortium)
- Finland, Oulu University Hospital OYS (Oulu ERNEpi Consortium)
- France, CHRU Nancy –Regional University Maternity Hospital of Nancy
- France, Strasbourg University Hospital (EGEE Consortium)
- France, Robert-Debré University Hospital, AP-HP (éPiRaReS Consortium)
- France, Adolphe de Rothschild Foundation Hospital (éPiRaReS Consortium)
- France, Pitié-Salpêtrière University Hospital, AP-HP (éPiRaReS Consortium)
- France, CHU Lille - Centre Hospitalier Universitaire de Lille, Epilepsy Unit
- France, Hospices Civils de Lyon (HCL), Epilepsy Departments
- France, Marseille University Hospitals, AP-HM, Epilepsy Dpt.
- France, Hospital Necker-Enfants Malades

# EpiCARE Members

- Germany, Bonn University Hospital
- Germany, Erlangen Universitätsklinikum
- Germany, Freiburg University Hospital, Epilepsy Centre
- Germany, Tübingen Universitätsklinikum, Epilepsy Dpt.
- Hungary, National Institute of Clinical Neurosciences - Országos Klinikai Idegtudományi Intézet
- Italy, IRCCS Istituto Neurologico Carlo Besta (Milano Consortium)
- Italy, ASST Niguarda Hospital (Milano Consortium)
- Italy, ASST Santi Paolo e Carlo Hospital (Milano Consortium)
- Italy, IRCCS Institute of Neurological Sciences of Bologna (INSB)-AUSL
- Italy, Azienda Ospedaliera Universitaria Meyer IRCCS, UO Neurologia Pediatrica
- Italy, IRCCS Istituto Giannina Gaslini
- Italy, Fondazione Istituto Neurologico Nazionale Casimiro Mondino
- Italy, Ospedale Pediatrico Bambino Gesù
- Italy, AOUI di Verona, Unità Operativa Complessa (UOC) di Neuropsichiatria Infantile
- Latvia, University Children's Clinical Hospital - Bērnu klīniskā universitātes slimnīca
- Lithuania, Hospital of the Lithuanian University of Health Sciences Kaunoklinikos
- Lithuania, Vilnius University, Institute of Clinical Medicine, Department of Neurology
- Luxembourg, Centre Hospitalier de Luxembourg (HUB)
- Malta, Mater Dei Hospital (HUB)
- Norway, Oslo universitetssykehus, Norwegian National Unit for Epilepsy
- Poland, The Children's Memorial Health Institute
- Portugal, Centro Hospitalar e Universitario de Coimbra
- Portugal, Hosp de Santa Maria, Centro de Referencia de Epilepsias Refractarias
- Portugal, Centro Hospitalar do Porto
- Romania, Alexandru Obregia Clinical Hospital
- Slovenia, Ljubljana University Medical Centre, Dpts. of Child, Adolescent and Developmental Neurology & Department of Neurology
- Spain, Hospital Clínic -Adults (HSJD-HC Consortium)
- Spain, Hospital Sant Joan de Déu (HSJD-HC Consortium)
- Spain, Hospital Del Mar-Parc de Salut Mar
- Spain, Hospital Universitario y Politecnico La Fe
- Sweden, Sahlgrenska University Hospital
- The Netherlands, University Medical Center Utrecht (Brain Center Rudolf Magnus)

# EpiCARE Management team

Considering the structure in Working Packages of the EU Grant for the coordination of an ERN and all the missions of the ERN EpiCARE the following competences are necessary for a comprehensive management of the network:

- Global Strategy (Health Policy) development;
- Administrative and Finances project management;
- Fostering Research activities and projects management;
- Case Patient Management System (CPMS);
- Registry and Data Sharing management;
- Design and planning of education programs and Guidelines
- Communication and Dissemination;
- Contact with Patient Advocates (ePAG) group.

The Project Managers employed by EpiCARE **work as a team**, under the responsibility of the EpiCARE Coordinator, who is reporting to the Executive Committee. They are recruited for their respective managerial skills in the above-mentioned domains and because they all:

- have the background and motivation to progressively penetrate the complexity of a discipline, such as epilepsy care;
- have the know-how to interact with researchers and clinicians from a wide range of backgrounds,
- are able to adapt to the constraints of the network's European expansion, including the use of at least 2 different languages and differences in time zones
- know-how to synthesise the experience gained from managing all of the network's missions, and
- to make decisions based on complete information.

They meet with the coordinator on a weekly basis and participate at the monthly call of the Executive Committee. They also serve as a direct liaison between the ExCo and the Working Groups.

# EpiCARE Management team



**Belén Trebino** (HSJD, Barcelona, Spain)  
Administration, Finances, Evaluation & Global coordination  
DG SANTE and HADEA liaison  
Executive Committee liaison  
WGs 10 and 18 liaison



**Laura Roig** (HSJD, Barcelona, Spain)  
Dissemination, Communication  
Patient empowerment  
WGs 3; 4; 6 and 19 liaison  
WG 17 leader



**Sébile Tchaicha** (HSJD, Barcelona, Spain - based in France)  
Fostering Research and innovation  
Scientific liaison other EU4Health projects  
Liaison European Consortium for Epilepsy Trials  
WGs 2; 7 and 16 liaison  
Cross-ERNs partnerships



**Nicola Openshaw-Lawrence** (HSJD, Secondment agreement GOSH, UK)  
Healthcare and CPMS activities

Capacity building and best practice sharing-Ukraine Educational webinars management  
WGs 5; 9; 11 and 19 liaison, and WG 20 leader



**Anne Robert** (HCL, Lyon, France)  
JARDIN project manager



**Martin Geroldinger** (SALK, Salzburg, Austria)  
Clinical Practice Guidelines

WGs 8; 13 and 14 liaison



**Johanna Van Hulle** (KUL, Leuven, Belgium)  
Registry and Data Management  
WGs 2 and 12 liaison



**Clotilde Guerineau** (ANT CONGRES, France)  
EpiCARE HELPDESK

WG14 and 17 liaison

# Contacts

To get **more information on the work groups**, create an account on the EpiCARE intranet (for EpiCARE members only) : [www.epi-care.eu/member](http://www.epi-care.eu/member)

To **join a work group** : contact [helpdesk@epi-care.eu](mailto:helpdesk@epi-care.eu) and briefly describe how you wish to contribute. We will redirect your request to the appropriate WG.

To **refer a patient to an EpiCARE centre**, please see the list of EpiCARE centres: <https://epi-care.eu/ern-epicare-centres/>.

If you are a member of EpiCARE and think that **the information given about your centre needs to be updated**, please provide the necessary information to [helpdesk@epi-care.eu](mailto:helpdesk@epi-care.eu), also copying the leader of your centre.

If you would like to **present a case for discussion with the participation of other experts**, (activity reserved to medical doctors' members of the ERN) please contact: [nicola.openshaw-lawrence@epi-care.eu](mailto:nicola.openshaw-lawrence@epi-care.eu). You will also need create an account giving you access to the CPMS platform (reserved to doctors working for EpiCARE medical teams): <https://epi-care.eu/case-discussions-epicare/>

If you wish to have information about the **prerequisites and procedures for your medical team to become a member of the ERN EpiCARE**, please refer to : <https://epi-care.eu/become-an-ern-member/> . Please note that the ERN coordination is not authorized to accredit new medical teams as members outside of official calls from the European Commission. Of course, individual experts wishing to contribute to any of the ERN activities are welcome. In such a case please inform the [helpdesk@epi-care.eu](mailto:helpdesk@epi-care.eu), also providing information about your fields of competence and expertise.

For more information on the **patient representatives and the ePAG**, please refer to: <https://epi-care.eu/epicare-patient-representatives/>. For any relevant questions you can also write directly to Vedrana, the ePAG secretary : [epag@epi-care.eu](mailto:epag@epi-care.eu)

For **any other question** on EpiCARE, contact [helpdesk@epi-care.eu](mailto:helpdesk@epi-care.eu)





# EpiCARE



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