



EpiCARE



Co-funded by the European Union



Press kit

The **ERN EpiCARE** is one of the **24 EU Reference Networks** created in 2017 by the European Commission to **enhance early diagnosis and state-of-the-art treatment of rare diseases**. ERNs are co-funded by the European Union.

The ERN EpiCARE is focused on **rare and complex epilepsies**. It is built around **52 members** in 26 European countries, who represent EU medical teams with a high level of expertise in all domains related to epilepsy care.

This network is coordinated by Professor Alexis Arzimanoglou, at the Hospices Civils of Lyon, France.



What are the European Reference Networks?



European Reference Networks, or ERNs, are **virtual networks** involving specialist healthcare providers across Europe. Their **goal** is to **take on rare and complex diseases** or conditions that require **highly specialised treatment and a concentration of knowledge and resources**. Between 6000 and 8000 rare diseases affect 30 million people in the European Union.

Created in 2017 and **co-financed by the European Commission**, the ERNs are part of a broader EU strategy to make the national and **European health systems more efficient, accessible and resilient**. By consolidating knowledge and expertise scattered across countries, the ERNs will give healthcare providers access to a much larger pool of expertise. This will result in better chances for patients to receive an **accurate diagnosis and advice on the best treatment for their specific condition**.

Patient cannot contact directly ERNs; they first need their primary physician to refer them to an epilepsy centre, who will carry out the necessary assessment and contact an EpiCARE centre if needed.



EpiCARE's history



"EpiCARE is on the beginning of its journey. And it is through the

collaboration between all of these centres, that we will strive to keep improving the standard of care for rare epilepsies, for all patients across the EU."

- Alexis Arzimanoglou

EpiCARE is the ERN focused on **rare and complex epilepsies**.

Since 2019, it is coordinated in France, by **Alexis Arzimanoglou**, head of the Paediatric Clinical Epileptology, Sleep Disorders and Functional Neurology Department at the University Hospital of Lyon.

Integrated in the **Research Department** (Direction de Recherche en Santé), the ERN EpiCARE is coordinated in the Hospices Civils de Lyon (Lyon University Hospitals).

The mission of hospitals is three-dimensional : improve and insure the continuity of medical and scientific knowledge for progression of care, insure that patients have access to the best care, and encourage innovative research to improve the standard of care. The HCL is proud to contribute to EpiCARE's goal of improving the knowledge on rare and complex epilepsies, and developing innovative treatments and diagnostic tools.

EpiCARE's coordination team is composed of :

- **Alexis Arzimanoglou**, coordinator of EpiCARE, HCL
- **Laurène Mathey**, coordination manager of EpiCARE, European Affairs Manager at the HCL
- **Nicola Openshaw-Lawrence**, E-learning and Data manager, CPMS coordinator, Great Ormond Street Hospital (London, UK)
- **Margaux Faure**, administration and project manager, European Affairs, HCL
- **Anne Robert**, communication manager, European Affairs, HCL
- **Sébile Tchaicha**, research projects manager, European Affairs, HCL



EpiCARE is composed of 38 full members and 12 affiliated. 14 new members were welcomed into the network in 2022.

The **Steering Committee**, composed of 27 members, meets once a month to discuss current issues and evaluate progress. A list of deliverables is expected by the European Commission, and each work group has expected results.

Once a year, a **General Assembly** is organised to bring together the Steering Committee, the leaders of each work groups and the representatives of each centre. This is the time to share progress, discuss hot topics and draw an outline of the future of the network.

This year, the General Assembly will take place in Lyon, on **February 17-18 2022**.

EpiCARE's activities & projects

Traditionally, **epilepsy** has been treated as a single disease, but these conditions are increasingly viewed as a **group of rare and complex diseases**. ORPHANET – the portal for rare diseases and orphan drugs – lists **137 disorders with epilepsy as the predominant symptom**. However, many patients remain undiagnosed and without access to treatment.

The network aims to deliver full access and utilisation of pre-surgical evaluation and epilepsy surgery, to **increase diagnosis** of rare epilepsies; to **enhance identification** of patients with treatable rare causes of epilepsy; to **increase access to specialised care**; and to **foster research on innovative causal treatments** in rare and complex epilepsies.

EpiCARE's members also develop and deliver **educational and training programs such as webinars and e-learning interactive cases, as well as guidelines**. They actively contribute to **clinical research programs and clinical trials** for the development of **new and safe innovative treatments**.

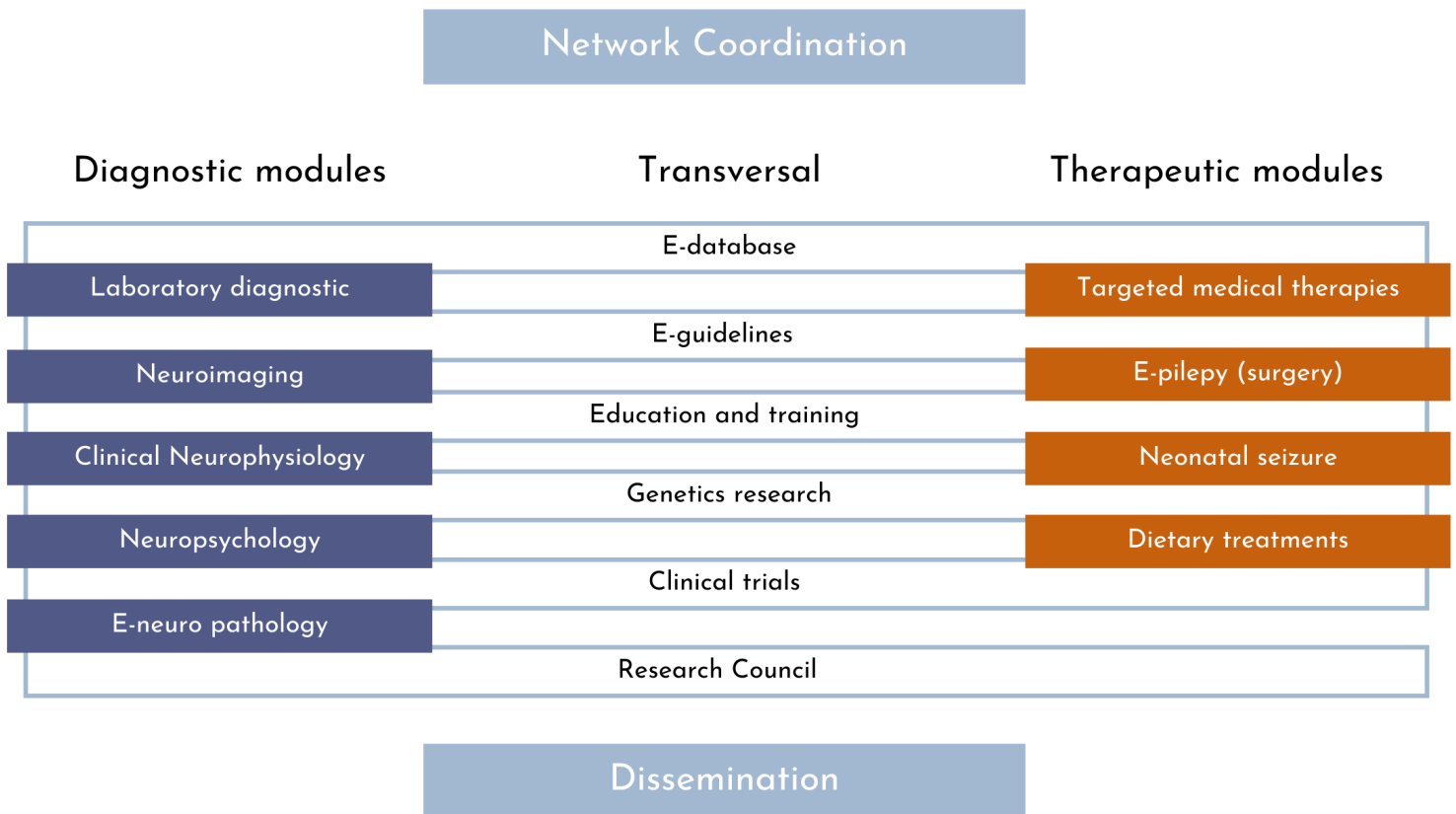
EpiCARE's activities include:

- **Sharing knowledge** in the form of publications, guidelines and protocols
- **Education and training** through webinars, practical tools and case discussions between clinicians to consult on particular cases
- Development of **highly specialized procedures** for diagnosis, innovative treatments and dissemination of knowledge through the Research Council
- **Networking** and **cooperation** between different stakeholders: clinicians, patient representatives, hospitals and epilepsy centres, the European Commission...

Structure

The activities of the network are divided on 2 parts : diagnostics tools, and treatment option. There are also transversal work groups, for a total of 16 work groups (see schema below)

EpiCARE's activities & projects



EpiCARE's current actions are varied :

- **Research Council:** the goal of the RC is to **support research conducted by EpiCARE members**, with the aim to improve the quality and quantity of research within the network.
- **European Rare disease research Coordination and support Action (ERICA):** this project promotes **inter-ERN research activities** by establishing firm collaborative ties with existing European and international infrastructures and consortia involved in rare disease research and innovation.
- **European Collaboration for Epilepsy Trials (ECET):** this project aims at **promoting the development of better treatments for people with epilepsy** and acquisition of knowledge for optimal application of epilepsy treatments
- **European Joint Programme for Rare Disease (EJP RD):** programme aiming to **create an effective rare diseases research ecosystem for progress and innovation**. The goal being to benefit people living with a rare disease.
- and many other projects in development! More information is available on the "EpiCARE's projects" section on the EpiCARE website.

Contact & more information

Website

The website www.epi-care.eu is EpiCARE's main communication tool. You will find informations for both patients and clinicians, as well as information on the latest events and congresses. The planning for EpiCARE's webinars is available on the website, as well as replays of past webinars.

You can also subscribe to EpiCARE's monthly newsletter, to get information on the network, its members, the coordination team and the patient representatives.

Social media

 /EpiCARE ERN

 @EpiCARE_ERN

 /EpiCARE - European Reference Network for Rare and Complex Epilepsies

Media kit

The Graphic Identity guidelines are available upon request. Please respect the recommendations regarding EpiCARE's logo and the "co-funded by the EU" mention.

Photos of members and events are available in high-definition upon request. There are some on our website as well.

For any other request regarding EpiCARE's communication, you can contact Anne Robert, communication manager :
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