

ERN on rare and complex epilepsies (EpiCARE)

Epilepsy affects at least six million people in Europe. Traditionally it has been treated as a single disease, but although the first clinical manifestations in the form of epileptic seizures may look similar, epilepsies can originate from a large number of different neurological aetiologies. Treatment choices, outcomes and the overall prognosis depend on which aetiologies are at work, and a prompt diagnosis, whenever possible, plays an important role.

When appropriately prescribed, traditional anti-seizure medications help nearly 70 percent of those affected to remain seizure free – but for patients suffering from refractory epilepsy, the clinical outlook is poor. Rare and complex epilepsies require multi-disciplinary management from the onset. Well-established care pathways and close collaboration with well-structured national networks for epilepsy care is essential.

The medical teams of ERN EpiCARE work to improve and increase diagnoses of the causes of rare epilepsies; enhance early identification of patients with treatable rare causes; increase access to specialised care; further develop and design innovative clinical trials for new anti-seizure medication through the European Collaboration for Epilepsy Trials (ECET); deliver full access to, and use of, early

pre-surgical evaluation and epilepsy surgery; and foster research on innovative diagnostic tools and causal treatments.

Several times each month the network organises patient case discussion sessions with the participation of EU experts in genetics, neuropsychology, drug management and pre-surgical evaluation. ERN EpiCARE has launched numerous knowledge generation activities, including interactive educational webinars and updates on clinical practice guidelines. The network with other ERNs and EU-funded initiatives such as the European Joint Programme on Rare Diseases (EJP RD), SOLVE-RD; ERICA and the transversal working groups on neurological disorders particularly involving ERN-RND and ERN EURO-NMD.

From the outset, the network has collaborated closely with all related scientific bodies such as the International League Against Epilepsy (ILAE), the European Paediatric Neurology Society (EPNS) and the European Academy of Neurology (EAN). In order to increase awareness of best practices and care pathways, ERN EpiCARE works with patient advocates from European Patient Advocacy Groups (ePAGs) to produce, for example, information leaflets on rare epilepsies, and patient centred clinical trials.

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