ERN on neurological diseases (ERN-RND)

The European Reference Network on Rare Neurological Diseases (ERN-RND) aims to address the unmet needs of more than 500 000 people living with RNDs in Europe. Due to significant phenotype and genotype heterogeneity of RND patients, 60 % of those affected are still undiagnosed.

ERN-RND seeks to address these gaps through virtual multidisciplinary consultation, increasing the number of patients in registries by 20 %, and aims for a 20 % improvement in case outcomes — the percentage of patients with a final diagnosis. Multidisciplinary care pathways will be developed in collaboration with the European Pathway Association and ORPHANET.

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The network builds on existing infrastructure by integrating a number of mature RND networks under the ERN-RND umbrella and supplementing functioning registries for conditions such as Huntington's disease and ataxia.

An external quality assessment scheme for the standardisation of key diagnostic tests will be developed in cooperation with the European Molecular Genetics Quality Network, ensuring all patients have access to the same diagnostic opportunities. ERN-RND will support training, research and innovation interventions, and ensure patients' voices are heard.

NETWORK COORDINATOR

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