

# ERN for rare neurological diseases (ERN-RND)

*ERN-RND creates and shares knowledge and coordinates care for patients affected by rare neurological diseases involving the most common central nervous system pathological conditions. It covers cerebellar ataxias and hereditary spastic paraplegias; Huntington's disease and other choreas; frontotemporal dementia; dystonia, (non-epileptic) paroxysmal disorders and neurodegeneration with brain iron accumulation; leukoencephalopathies; and atypical parkinsonian syndromes.*

The network unites expert centres and affiliated partners in 24 European countries, as well as patient representatives. It focuses on highly specialised healthcare services such as next generation sequencing diagnostics, deep brain stimulation and advanced therapies, and generates and disseminates both overarching and disease group-specific knowledge.

ERN-RND develops clinical best practice guidelines for some RNDs, best practice recommendations for neurorehabilitation and transition, as well as care standards such as the composition of multidisciplinary teams.

Disease expert groups develop and agree care pathways including diagnostic flowcharts and therapeutic algorithms, as well as disease scales to assess different aspects of rare neurological diseases.

Patients with unclear diagnoses are discussed via the CPMS. ERN-RND is one of four networks participating in the Solve-RD - Solving the Unsolved Rare Diseases project, and its training and education programme underpins an RND curriculum for healthcare professionals. The network facilitates trial-readiness and care quality through an ERN-RND registry,

including data on all patients seen at ERN-RND centres and providing a unique overview of existing genotype-based cohorts.

ERN-RND cooperates with the European Academy of Neurology (EAN); the European Paediatric Neurology Society (EPNS); the European section of the International Parkinson and Movement Disorder Society (MDS); the European Federation of Neurological Associations (EFNA); and the European Academy of Childhood Disability (EACD). With the other two 'Neuro-ERNS' - EURO-NMD and EpiCARE - ERN-RND has established nine working groups.

## NETWORK COORDINATOR

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