ERN on bone disorders (ERN BOND)

Rare bone diseases encompass disorders of bone formation, modelling, remodelling and removal, and defects of the regulatory pathways of these processes. They result in short stature, bone deformity, teeth anomalies, pain, fractures and disability, and can adversely influence neuromuscular function and haemopoiesis.

ERN BOND brings together all rare bone diseases - congenital, chronic and of genetic origin - which affect cartilage, bones and dentin. The network currently focuses on osteogenesis imperfecta (OI), X-linked hypophosphataemic rickets (XLH) and achondroplasia (ACH) as exemplars, based on disease prevalence, diagnostic and management difficulty, and novel emergent therapies. In future, as systematic approaches are established, ERN BOND will move on to rarer diseases.

Working with patients, ERN BOND develops patient-reported outcome and experience measures, as well as guidelines for the development and dissemination of best practice. As new therapeutics are developed, the network aims to ensure rapid access to studies for affected patients.

ERN BOND enables skill development through eHealth and telemedicine platforms, alongside working visits, training courses and dissemination activities. The network aims to reduce diagnosis time through fewer inappropriate tests, more accurate diagnosis and new viable treatments.

NETWORK COORDINATOR

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