



**European
Reference
Network**

for rare or low prevalence
complex diseases

Network
Connective Tissue
and Musculoskeletal
Diseases (ERN ReCONNET)

HOW TO GET INVOLVED IN ERN ReCONNET

European Reference Network on
Rare and Complex Connective Tissue
and Musculoskeletal Diseases

As a patient/patients' organisation

One of the most relevant **added value** of the ERN ReCONNET is the **involvement** of Patients' Representatives within all the activities of the Network.

To ensure the participation of patients and patients' organisations in the activity of the ERNs, EURORDIS created the **European Patient Advocacy Groups** (ePAGs) as forums to optimise the involvement of patient representatives of the rare disease community in the 24 ERNs.

ePAG aim to represent **the voice of patients** within ERNs to ensure the needs of people living with a rare disease are included in the strategic and operational delivery of the Network. ePAGs create **a bridge** between the ERN and the patient community, to ultimately ensure that ERN services can answer to the **needs and expectations** of rare disease patients and therefore improve access to high quality **diagnosis, care and treatment**.

The ERN ReCONNET ePAG represents the **community** of rare and complex connective diseases patients. If you want to be involved, please **contact us**.

As a healthcare provider

Each healthcare provider (HCP) wishing to become a member of an ERN has to pass an **assessment process** based on the criteria in Delegated Decision (2014/286/EU) Annex II and on the Implementing Decision (2014/287/EU). This assessment will be composed of several steps such as the formal support/endorsement by the Member State, an eligibility check and a final approval by the Board of Member States.

Members of the ERN ReCONNET are HCPs that have **knowledge and expertise** on rare and complex connective tissue diseases and that fulfill the criteria and conditions set in the Commission Delegated Decision of 10 March 2014.

New calls to recruit HCPs will be launched regularly by the European Commission. If you wish to join the ERN ReCONNET, please **contact us**.

HOW TO GET INVOLVED IN ERN ReCONNET

As an expert in rare and complex connective tissue diseases

The ERN ReCONNET welcomes the participation of [single experts](#) in the field of rCTDs. Experts collaborating to the ERN ReCONNET should comply with a set of criteria established by the ERN ReCONNET Steering Committee.

If you want to collaborate to the activities of the ERN ReCONNET as a single expert, please [contact us](#).

Virtual Consultation

The European Commission has provided ERNs with a [secure web-based application](#) for the diagnosis and treatment of rare or low prevalence complex diseases or conditions across national borders.

The [Clinical Patient Management System](#) (CPMS) enables clinicians and researchers to enrol patients to collaborate actively and share [patient data](#) within and across ERNs using comprehensive data models. Bringing together highly specialised healthcare providers in complex, rare or low prevalence diseases the CPMS can contribute to the [diagnose, treatment and improvement of the quality of life](#) of people living with rare diseases.

Do you have a clinical case to discuss? [Contact us!](#)

Contacts



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ERN ReCONNET



ERN ReCONNET was funded by the European Union's Health Programme (2014-2020)

ERN ReCONNET is one of the 24 European Reference Networks (ERNs) approved by the ERN Board of Member States. The ERNs are supported by the European Commission.

For more information about the ERNs and the EU health strategy, please visit ec.europa.eu/health/ern

