



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 or 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**.

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## As external expert

The ERN ReCONNET welcomes the participation of **individual experts** in the field of rare and complex connective tissue diseases (rCTDs). External experts may be individual **clinicians** or **healthcare professionals** with an expertise in the field of rCTDs that request to participate to the Network activities.

After a formal assessment of the required **criteria**, external experts can be involved in ERN ReCONNET activities based on their expertise and on their willingness to contribute to the project. These experts are external with respect to the **Healthcare Providers** (HCPs) full members of the ERN ReCONNET.

### Are you interested in being an external expert?

Should you be interested in becoming an ERN ReCONNET external expert, please send a **formal application** to the Network Coordinator with updated Curriculum Vitae, a list of publications, your research activities and the disease(s) you would like to be considered for. The **Steering Committee** will then assess your request according to defined **criteria** and select the areas of interest in which you can be included.

## Virtual Consultation

The European Commission has provided ERNs with the **Clinical Patient Management System** (CPMS), a **secure web-based application** for the diagnosis and treatment of rare or low prevalence complex diseases or conditions across national borders. The 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!**

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