

OUR PATIENT REPRESENTATIVES

The ERN ReCONNET European Patient Advocacy Group

ERN ReCONNET has established a formal partnership with patients' representatives (the European Patient Advocacy Group - ePAG Advocates) that are actively integrated in all the actions, activities, and initiatives of the Network.

The patient organizations that are taking part of our Network are:

- Asociación Española Síndrome Antifosfolípido
- Lupus Europe
- Sjögren Europe
- Asociación Nacional de Síndromes de Ehlers-Danlos, Hiperlaxitud y Colagenopatías
- Federation of European Scleroderma Associations (FESCA)
- Bindweefsel.be
- Liga Portuguesa Contra as Doenças Reumáticas Association of Patients with Inflammatory Rheumatic Diseases in Transylvania
- Relapsing Polychondritis Awareness and Support
- Liga Portuguesa Contra as Doenças Reumáticas Romanian Association of Relapsing Polychondritis Patients
- Let's stick together Association
- Czech League against the Rheumatism
- German Society for Muscular Disorders.

Stay connected

CONTACT US

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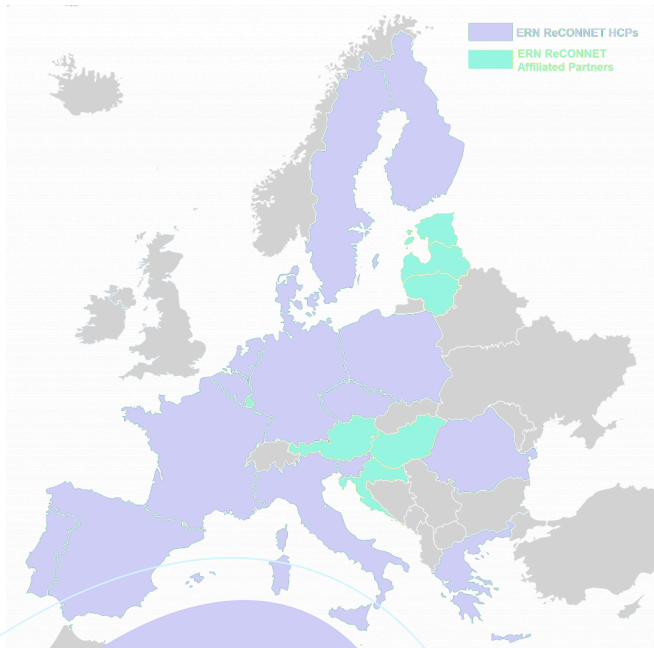


Funded by the
European Commission

ERN ReCONNET: The European Reference Network on Connective Tissue and Musculoskeletal Diseases

The mission of the ERN ReCONNET is to create a framework aimed at improving quality, safety and access to highly specialised and sustainable healthcare for European patients with rCTDs. The ERN ReCONNET is a multi-stakeholder infrastructure going beyond geographical boundaries, whose purpose is to act as a hub to understand needs, share feedback, and expertise for HCPs, patients, families, and other stakeholders involved in rCTDs (other networks, authorities, health systems, private sectors, etc.).

ERN ReCONNET involves 63 Healthcare Providers: 54 Full Members and 9 Affiliated Partners over 23 European countries.



ERN ReCONNET covers the following rCTDs:

- Antiphospholipid syndrome (APS)
- Ehlers-Danlos syndromes (EDS)
- Idiopathic inflammatory myopathies (IIM)
- IgG4-related diseases (IgG4)
- Mixed connective tissue diseases (MCTD)
- Relapsing polychondritis (RP)
- Sjögren's syndrome (SS)
- Systemic lupus erythematosus (SLE)
- Systemic sclerosis (SSc)
- Undifferentiated connective tissue diseases (UCTD)

Our Activities

TOGETHERN RECONNET REGISTRY



The European Registry Infrastructure for data harmonization in rCTDs - **TogethERN ReCONNET**, aims at integrating all existing and newly developed registries on rCTDs across Europe to:

- Understand the natural disease course
- Characterize diseases in the early phases
- Map disease history
- Identify different disease phenotypes
- Distinguish predictive variables for disease outcomes.

THE CLINICAL PATIENT MANAGEMENT SYSTEM (CPMS)



The CPMS is a secure IT platform to facilitate cross-border medical discussions and support the ERNs in the diagnosis and treatment of rare and low prevalence complex diseases or conditions.

EDUCATION AND TRAINING

ERN ReCONNET organizes a wide range of educational and training activities, such as:

- Educational webinars
- Online accredited training course on rCTDs
- Educational exchanges in ERN ReCONNET centres
- ERN ReCONNET Scientific Congress
- ERN ReCONNET Young Working Group

RESEARCH AND QUALITY OF CARE

ERN ReCONNET promotes research projects on rCTDs, such as:

- Quality measures in Transition of care in rCTDs
- Patient's care pathways
- Promotion of good practices sharing

CLINICAL PRACTICE GUIDELINES & TOOLS

ERN ReCONNET develops guidelines and tools in rCTDs, often in cooperation with other initiatives.

- Red Flags for early diagnosis and referrals
- Points to consider
- Transition of care

PATIENT PARTNERSHIP

ERN ReCONNET is strongly devoted to promote an effective Patient Partnership, with a dedicated Working Group that is developing strategies and initiatives towards this ambitious goal.