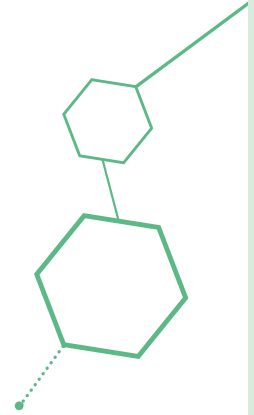


ERN on connective tissue and musculoskeletal diseases (ERN ReCONNET)



Rare connective tissue and musculoskeletal diseases (rCTDs) comprise different diseases and syndromes which have a considerable impact on patient well-being. They include hereditary conditions; systemic autoimmune diseases such as systemic sclerosis; mixed connective tissue diseases; inflammatory idiopathic myopathies; undifferentiated connective tissue diseases; and anti-phospholipid syndrome.

ERN ReCONNET is developing a framework for the delivery of high quality, innovative, sustainable and equitable standards of care and practice which will give European patients with rCTDs better access to healthcare.

Thanks to collaboration between full members, ePAG representatives and affiliated partners, ERN ReCONNET has developed peer-reviewed publications including the latest clinical practice guidelines; unmet needs in patient education; optimisation of patient care pathways; and the impact of COVID-19 on rCTDs. The network has also delivered a methodology for creating organisational models for rare disease patient care pathways; a European registry infrastructure for data harmonisation in rCTDs which aims to integrate all existing and newly developed registries on rCTDs across Europe; webinars

for healthcare professionals and patients on ERN ReCONNET topics; and lay versions of clinical practice guidelines.

Patient representatives are deeply involved in all ERN ReCONNET activities, playing a key role in drafting and reviewing publications, providing essential information on patients' needs to improve pathways, and helping to improve disease knowledge and management. They participate both as webinar panelists and attendees, develop lay versions of publications, support assessment procedures for new members, and are involved in governance.

The close collaboration of the different stakeholders involved in the network represents one of the main added values of ERN ReCONNET, which will continue improving the lives of people living with rCTDs.



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