ERN on connective tissue and musculoskeletal diseases (ERN ReCONNET)

Rare connective tissue and musculoskeletal diseases (rCTDs) comprise a large number of diseases and syndromes, with a tremendous impact on patient well-being. These include hereditary conditions, and systemic autoimmune diseases such as systemic sclerosis, mixed connective tissue diseases, inflammatory idiopathic myopathies, undifferentiated connective tissue diseases, and anti-phospholipid syndrome. Delayed diagnosis, particularly for rare or complex presentations, is a common problem.

The network will improve scientific knowledge of rCTDs and facilitate the creation of large databases to identify new clinical or biological markers to aid diagnosis.

This network groups rCTDs into three main thematic groups: rare autoimmune, complex autoimmune, and rare hereditary connective tissue and musculoskeletal diseases.

ReCONNET aims to improve early diagnosis, patient management, care delivery and virtual discussion of clinical cases within the network and with affiliated centres. The use of information technologies (IT) will facilitate interaction between centres. The network will improve scientific knowledge of rCTDs and facilitate the creation of large databases to identify new clinical or biological markers to aid diagnosis.

Educational programmes for patients and families will be developed and disseminated, and new guidelines and quality measures will be implemented. Improved therapeutic protocols and greater patient involvement are also priorities.

NETWORK COORDINATOR

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