



Prague
9–11 April 2025



ERN ReCONNET. 2nd International Congress

Prague, 11–14 April 2025

The idea of the European Reference Networks (ERNs) was conceived in 2011 as a system of cross-border networks that bring together European centres of expertise to combat and share knowledge concerning rare diseases occurring in Europe. The aim of establishing the ERNs, according to Directive 2011/24/EU, was to enable specialists in Europe to discuss the cases of patients affected by rare diseases and provide advice on appropriate diagnosis and treatment. Finally, the first ERNs were launched in March 2017, their number eventually reaching 24. At present (as of 2024), the ERNs cover 1619 specialised centres in 382 hospitals in the 27 EU Member States and in Norway.

One of the ERNs – the European Reference Network on connective tissue and musculoskeletal diseases (ReCONNET) – is devoted to following rare autoimmune inflammatory rheumatic diseases: antiphospholipid syndrome (APS), 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), and non-inflammatory Ehlers-Danlos Syndromes (EDS). Currently ReCONNET involves 63 healthcare providers (HCP), 54 full members, and 9 affiliated partners (APs) with 23 European countries committed to this project. In ReCONNET, groups dealing with specific problems are actively involved in education, development of recommendations for treatment of rare diseases, and the search for early diagnostics solutions and new directions of treatment. Importantly, each of the thematic and task groups cooperates with patient representatives (Fig. 1).

The 2nd International Congress on rare and low-prevalence connective tissue and musculoskeletal diseases, which took place in Prague, provided an opportunity for actively engaged members of the network to meet each other, sharing knowledge and experience (Fig. 2).



Fig. 1. Representatives of the Sjögren's syndrome group and with Prof. Marta Mosca Coordinating HCP ERN ReCONNET (from left Gaetane Nocturne, Coralie Bouillot, Marta Mosca, Ana Veira, Chiara Baldini, Maria Mašlíňská).



Fig. 2. Participants of the ReCONNET Congress.

For three days, outstanding specialists representing individual groups presented lectures on rare diseases, their pathogenesis and treatment, social aspects of the perception of rare diseases, and unmet needs of patients. In particular, a modern approach to the needs of patients was presented, taking into account their psychosocial problems and access to treatment.

Poster abstracts were also presented, which allowed for a discussion with their authors.

Thanks to the presence of participants from various countries, it was possible to exchange experiences and confront problems encountered by different members in the management of connective tissue and musculoskeletal diseases.

The link of the topics of the lectures can be found at <https://www.ern-reconnetcongress.com/topics>

The congress was very successful, giving not only the opportunity to deepen participants' knowledge on the subjects that ReCONNET members deal with, but also to establish greater cooperation between doctors/researchers and centres in which they work.

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