



# ERN ReCONNET Newsletter

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September 2022

## New ERN ReCONNET Working Groups



The main objectives of ERN ReCONNET are:

- realisation of the potential of European cooperation among rCTDs stakeholders, by providing a stable and fully functioning European infrastructure on rCTDs;
- provision of highly-specialised care for rCTDs patients and promotion of improvements in the cost-effective delivery of diagnosis, management and monitoring of rCTDs patients;
- pooling, advancing and exchanging of knowledge and information on rCTDs by providing training and education for rCTDs stakeholders and by facilitating the mobility of expertise;
- stimulating and encouraging collaborative patient-centered research in rCTDs;
- promoting the empowerment and the involvement of rCTDs patients in the rCTDs community.

On these premises, 5 transversal Working Group are formally established in ERN ReCONNET:

- **Education and Training**
- **Patients' Partnership**
- **Research and Quality of care**
- **Registry and eHealth**

- ERN young.

All Kick Off Meetings have been held in September 2022.

[More info](#)

## First ERN ReCONNET International Congress on rare and low-prevalence connective tissue and musculoskeletal disease



On behalf of the Congress Committee, it is a great pleasure to invite you to take part to the first ERN ReCONNET International Congress on rare and low-prevalence connective tissue diseases which will take place in **Brussels, Belgium**, on **April 20–22, 2023**.

Knowledge, awareness and a patient-centred approach have been cornerstones of the activity of ERN ReCONNET, the European Reference Network on Rare and Complex Connective Tissue and Musculoskeletal Diseases, in its first five years of activity and the programme reflects the ERN mission, covering important topics in the diagnosis and management of rare and complex diseases such *epidemiology, diagnosis and clinical management, biobanking and registries, quality*.

The programme has been developed to integrate the perspective of the different stakeholders involved in rare diseases management. For this reason we expect that the congress will be of interest not only for specialists but also for people living with a rare disease, caregivers, clinicians, policy makers, industry, and will represent an opportunity

for rare and complex connective tissue diseases community to meet, work together and find new inspirations for research, diagnosis and therapy.

We are excited about meeting you at this innovative conference that, we hope, will stimulate and foster collaborations all around Europe! Therefore, we warmly invite to present and share original and significant experience, research and innovation in the field of rare and complex connective tissue diseases.

We are looking forward to welcoming you in Brussels.

*Marta Mosca on behalf of the Congress Committee*

[More info](#)



Don't miss the chance to send your **abstract** to the First International Congress on rare and low-prevalence connective tissue and musculoskeletal diseases. The deadline is **15th November 2022**.

[Submit your abstract](#)

## ERN ReCONNET monitoring



ERNs and their members shall be periodically evaluated, at the latest every five years after their approval. For this reason, this year the ERNs and the members that joined in 2017 will be evaluated (the evaluation doesn't concern the members who joined ERN in 2022).

The evaluation is aimed at verifying whether the Network achieves the quality standards and objectives set. The

evaluation will also be a way to obtain an overview of the gaps and opportunities of the project in order to optimize subsequent actions.

The European Commission developed a set of documents dedicated to the ERN Evaluation and all the members received them in July 2022 and in September. Also patients representatives play a key role in this evaluation process: for this reason, EURORDIS developed resources to help patients. All these documents are available on our website.

[More info on monitoring](#)

## New ERN ReCONNET ePAGs



Welcome to [Sue Farrington](#), ePAG representative for the Federation of European Scleroderma Associations [FESCA](#). Find out more about our new [ePAGs](#) (and meet our old ones) on our dedicated webpage.

It's always time to join the European Patient Advocacy Groups! ePAG Advocates represent the interests of the patient community and ensure that their needs are met by the ERNs. Thinking of getting involved in the ERN ReCONNET as an ePAG advocate? This EURORDIS short [guide](#) can help you to decide whether to apply.

[ERN ReCONNET ePAGs](#)

**Lupus 100, a cooperation between  
Lupus Europe, FAI<sup>2</sup>R, ERN ReCONNET  
and Éditions Katana Santé**



Find reliable, quality answers on the 100 most frequent questions about lupus, written by leading lupus doctors in collaboration with patients.

Lupus 100 is a cooperation between [Lupus Europe](#), [FAI<sup>2</sup>R](#), [ERN ReCONNET](#) and [Éditions Katana Santé](#)

Lupus 100

## "Health System Resilience in rare and complex diseases: context looking for the determinants" webinar



Health policymakers are currently paying increasing attention to the resilience of healthcare systems, due to several technical failures that occurred in response to major health shocks, most notably the COVID-19 pandemic and the Ebola epidemic. These shocks disrupted many activities in different sectors of the health system, including the treatment of rare diseases. Because of their unique demands and the requirement for ongoing care, vulnerable groups, such as patients with rare diseases, deserve particular attention.

In this webinar, held by [Gelareh Emami](#) and prof. [Giuseppe Turchetti](#) ([Sant'Anna School of Advanced Studies](#)), we launch a [survey](#) that aims to identify resilience determinants in the context of rare and complex diseases. This webinar presents an overview of Sjögren's, its hallmarks, complexities, and subtleties, in such a way that it will hopefully empower patients to know how to explain to others how the disease impacts their lives at different levels (disease burden). It is

also intended to validate symptoms and reassure patients, so that they feel less isolated in their daily struggles.

Watch the webinar

## ERNs for Ukraine



All 24 European Reference Networks launched a dedicated website and social media campaign to collect information to help health professionals to find support for Ukrainian patients with rare diseases: diagnosis, treatment, advice.

ERNs Health care providers, particularly those located in the countries currently receiving large numbers of refugees (Poland, Slovakia, Hungary, Romania) are ready to help Ukrainian patients with rare / very rare diseases, for specific diagnostic procedures and treatment. Those centers work in close cooperation with the ERNs they belong to.

The <https://erncare4ua.com> website should provide information on how to get support.

More info

## **New ERN ReCONNET article "An overlook on the current registries for rare and complex connective tissue diseases and the future scenario of TogethERN ReCONNET"**



**Patient registries** play a crucial role in supporting clinical practice, healthcare planning and medical research, offering a real-world picture on rare and complex connective tissue diseases (rCTDs). ERN ReCONNET launched the **first European Registry Infrastructure** with the aim to plan, upgrade and link registries for rCTDs, with the final goal to promote a harmonized data collection approach all over Europe for rCTDs.

An online survey addressed to healthcare professionals and patients' representatives active in the field of rCTDs was integrated by an **extensive database search** in order to build a mapping of existing registries for rCTDs.

A total of 140 registries were found, 38 of which include multiple diseases. No disease-specific registry was identified for relapsing polychondritis, mixed connective tissue disease and undifferentiated connective tissue disease.

This **overview on the existing registries for rCTDs** provides a useful starting point to identify the gaps and the strengths of registries on the coverage of rCTDs, and to develop a common data set and data collection approach for the establishment of the TogethERN ReCONNET Infrastructure.

[Read the article](#)

## ERN Exchange Programme



The **ERN Exchange Programme** has restarted and the next exchanges will take place between november 2022 and january 2023.

In an [European Commission video](#), some of the professionals who recently took part in an ERN Exchange share their experiences, and describe how Exchanges contribute to enhancing access to high quality care for

patients with rare diseases and complex disorders in EU Member States.

[More info](#)

## ERN ReCONNET at ACR 2022



ERN ReCONNET will be present at [ACR 2022](#) with a non-profit booth in the [Exhibit Hall](#) (n. 1017).

If you are in Philadelphia, come visit us!

## Flash News



### Board of Network Meeting

The Board of Network meeting has been held on 17 October 2022. It was an opportunity to update the participants on ERN ReCONNET Congress, ERN Evaluation, ERN Coordinators' Meeting, Working Groups, and CPMS.



### ERN Coordinators Meeting

During the ERN Coordinators meeting that took place in Brussels on 4th October, the Commission introduced the new unit that will manage the ERNs. The new Unit is based in Luxembourg and the Head of the unit is Donata Meroni.



### Joint action on ERNs' integration

The joint action aimed at integrating the ERNs in the National Health Systems was approved in January 2022. Member States and entities will contribute with different activities in the respective work packages.

# **EJP RD Resources and Funding Opportunities**





## Research Mobility Fellowships

The call for **Research Mobility Fellowships** aims to support PhD students, Postdocs and medical doctors in training to undertake scientific visits fostering specialist research training outside their countries of residence.

The exchange can be carried out either:

- within the same ERN (Full Members and Affiliated Partners), OR
- between different ERNs (Full Members and Affiliated Partners), OR
- between ERN Full Members / Affiliated Partners and non-ERN institutions.

Either home or host (secondment) institution must be a Full Member or Affiliated Partner of an ERN at the time when the application is submitted, as well as during the proposed period of the training stay. The call is open until **November 13th, 2022**.

[More info](#)



## Networking Support Scheme

The aims of the **Networking Support Scheme** are to encourage sharing of knowledge on rare diseases or rare cancers between health care professionals, researchers and patients in new or expanding research networks by funding networking events, and to enable or increase the participation of usually underrepresented countries in Europe in new and in expanding research networks on rare diseases or rare cancers.

Applicants can choose between the format of a **face-to-face meeting**, an **online meeting** or a **hybrid meeting** if networking is secured.

The last collection date for this funding scheme in the EJP RD is **December 1, 2022** at 14.00 (CET).

Events may be organized between **February 15, 2023** and **September 1, 2023**.

[More info](#)

## New sections on ERN ReCONNET website



The ERN ReCONNET website is constantly updated: find out all the updates by visiting it!

Website

## Past webinars



Find out the ERN ReCONNET webinars: they are available on our website and on our YouTube channel.

Past webinars

## Clinical Patient Management System



The **Clinical Patient Management System** (CPMS) aims at supporting ERNs in improving the diagnosis and treatment of rare or low prevalence complex diseases across national borders of Member States in Europe.

The CPMS is a secure **Software as a Service** (SaaS) that enables health professionals to enrol patients using comprehensive data models. Health professionals can use the CPMS to collaborate actively and share patient within and across ERNs.

For more information on how to access the CPMS and how to

request a virtual consultation, please contact us at:  
[helpdesk.reconnet@ao-pisa.toscana.it](mailto:helpdesk.reconnet@ao-pisa.toscana.it)

[More info](#)

## CPMS National Hubs



The ERN ReCONNET **CPMS National Hubs** serve as national contact point to support the usage and the dissemination of the CPMS at national/local level, and as national reference contact for specialists, general practitioners and other healthcare professionals in each country in order to provide information on the functioning of the platform.

The National Hub also contribute to connecting even the more remoter healthcare providers and patients to highly specialised services of the ERN ReCONNET.

The ERN ReCONNET National Hubs developed the translation of the **CPMS guides** into French, German, Dutch, Italian, Portuguese and Romanian, available at this [link](#).

[More info](#)

## ERN ReCONNET IT Services



You can find all information about the **ERN ReCONNET IT Services** on the ERN ReCONNET website, with additional **CPMS training videos**.

[More info](#)

## SOCIAL MEDIA CHANNELS



## ERN ReCONNET YouTube Channel and Twitter page

Don't forget to subscribe to the ERN ReCONNET official [YouTube channel](#) and to follow us on the ERN ReCONNET [Twitter page](#) @ern\_reconnet



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ERN ReCONNET is one of the 24 European Reference Networks (ERNs) approved by the ERN Board of Member States. The ERNs are supported by the European Commission. For more information about the ERNs and the EU health strategy please visit [ec.europa.eu/health/ern\\_en](http://ec.europa.eu/health/ern_en)



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