



# ERN ReCONNET Newsletter

Issue n. 17  
July 2022

## New ERN ReCONNET Disease Coordinators elected

After a voting procedure involving the Board of Network, the new ERN ReCONNET **Disease Coordinators** were elected:

**APS:** Maria Tektonidou and Savino Sciascia

**EDS:** Fransiska Malfait and Alberto Sulli

**IIM:** Ingrid Lundberg and Alain Meyer

**IgG4:** Emanuel della Torre and Tobias Alexander

**MCTD:** Marzena Olesińska and Benjamin Chaigne

**RP:** Laurent Arnaud and Simona Rednic

**SLE** Laurent Arnaud and Maarten Limper

**SS:** Xavier Mariette and Vasco Romão

**SSc:** Vanessa Smith and Marco Matucci Cerinic

**UCTD:** Luca Iaccarino and Cristina Pamfil

We wish you good work!

## New ERN ReCONNET members of the extended Steering Committee elected



In the same voting procedure the Board of Network elected the new members of the ERN ReCONNET **extended Steering Committee**:

Patricia Carreira ([Hospital Universitario 12 de Octubre](#))

Andrea Doria ([AOU Padua](#))

Christophe Richez ([CHU de Bordeaux](#))

Madelon Vonk ([Radboud Univ. Medical Centre Nijmegen](#))

Welcome to the new members!

## New ERN ReCONNET ePAGs



Welcome to [Eva Collado-González](#), ePAG representative for Ehlers–Danlos Syndrome and member of Spanish [ANSEDH](#) · Asociación Nacional Síndrome de Ehlers–Danlos e Hiperlaxitud.

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

## ePAG Guide on Patient Involvement in Clinical Practice Guidelines and Other Clinical Decision Support Tools



Based on the ePAG exchange of good practices webinar focused on the topic of [Patient involvement in identifying](#)

[unmet needs on clinical patient guidelines](#), [EURORDIS](#) developed the **ePAG Guide for Patient Involvement in the Development of Clinical Practice Guidelines and Clinical Decision Support Tools**.

Many of the ERN ReCONNECT good practice are mentioned in the Guide, such as [publications](#) and the ERN ReCONNECT webpage [What you need to know](#).

ePAG Guide

## **ePAG exchange of Good Practices: Designing Surveys**



The EURORDIS webinar "Building Good Practices: Designing surveys" held on **10th May 2022** by [Silvia Aguilera](#), [Ilaria Galetti](#) and [Diana Marinello](#) is now available online.

This webinar present an overview of ERN ReCONNECT good practice on co–designing surveys for rare diseases, focusing on surveys on Clinical Practice Guidelines, surveys on educational needs, and on some practical tips.

Watch the webinar

## **"How to explain Sjögren's syndrome to your family and friends" webinar**



This webinar, held by [Ana Vieira](#), [Coralie Bouillot](#) and [Éric Hachulla](#), 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](#)

## **ERN ReCONNET posters on Systemic autoimmune diseases and vaccines**



Thanks to the commitment of ePAGs and members, ERN ReCONNET developed a poster on Systemic autoimmune diseases and vaccines, translated in six languages (Dansk, Italiano, Nederlands, Português, Español, Français), and made available on our website.

[Downloadable posters](#)

## **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 ReCONNECT, 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](#)

## **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](#)

## ERN ReCONNET Supplement



ERN ReCONNET developed and published the Supplement **Rare inside rare: rare aspects of rare and complex connective tissue and musculoskeletal diseases** on [Clinical Experimental Rheumatology](#).

This supplement is devoted to the rarest forms of the diseases covered by the network, and includes also a review by the entire network, **The added value of a European Reference Network on rare and complex connective tissue and musculoskeletal diseases: insights after the first 5 years of the ERN ReCONNET**, which is aimed not only at reporting a summary of the main activities and milestones reached so far, but also at celebrating the first 5 years of the ERN ReCONNET, in which the members of the network built together one of the 24 infrastructures that are hopefully going to change the scenario of rare diseases across the EU.

## Survey on pregnancy



It is still possible to participate in the **Survey on the state of the art on challenges and good practices related to pregnancy and family planning in rare and complex diseases**, developed by the Pregnancy Working Group.

One is dedicated to [healthcare professionals](#) and one is dedicated to patients and caregivers in 8 languages [Bulgarian](#) [Dutch](#) [Italian](#) [French](#) [German](#) [English](#) [Spanish](#) [Polish](#)

## ERN Exchange Programme has restarted



The [ERN Exchange Programme](#) has restarted!

The first three exchanges have been take place between the Associated National Centre [Pauls Stradins Clinical University Hospital](#) (Riga, Latvia) and the HCP full member host [IRCCS AOU San Martino](#) (Genoa, Italy).

You can now apply to the second edition of the ERN ReCONNET Exchange Programme. Are you:

- a **healthcare professional** (researcher, clinician, nurse or other staff member of the HCP) belonging to ERN ReCONNET Full Members and Affiliated Partners, or
- one of the **ePAG Advocate** of ERN ReCONNET?

Would you be interested to expand your clinical and organisational knowledge on improving care, to learn from other health care professionals and to strengthen your

professional network? Then the ERN exchange programme might be an interesting opportunity for you! This programme, launched and supported by the European Commission, offers you the chance to go on an exchange and visit health care professionals from a hospital in another country. Travel costs and daily allowance are included. The deadline to apply for the first round of the second edition is the **5th September 2022**. You can apply at the following link.

[Apply here](#)

## ERN ReCONNET at EULAR 2022



ERN ReCONNET was present at [EULAR 2022](#) with a booth at the EULAR Village. We had many visits from old and new members and ePAGs, and from curious (and then interested) people.

## EJP RD Resources and Funding Opportunities







## **Innovation Management Toolbox**

The **Innovation Management Toolbox** is a free to use **reference library of resources in rare disease translational medicine**.

It has been designed to provide investigators with self-help resources specific to their needs.

The Innovation Management Toolbox empowers researchers to conduct rigorous translational research.

It aims to help researchers independently navigate the complexities of translation and give a clear overview of the communities that are available to help them. The ultimate impact of these activities is to reduce uncertainty and inefficiency in the academic translational research process, resulting in faster development and more patient-centric research outcomes.



## **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 Call for the NSS is open from **July 1, 2022** after a pause. Events may be organized between **February 15, 2023** and **September 1, 2023**.

[More info](#)

[More info](#)

## New sections on ERN ReCONNECT website



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

[Website](#)

## Past webinars



Find out the ERN ReCONNECT 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**.

# 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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