ERN ReCONNET Newsletter

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ERN ReCONNET article published on *Nature Reviews Rheumatology*

ERN ReCONNET has just published the free to view article "The impact of COVID-19 on rare and complex connective tissue diseases: the experience of ERN ReCONNET" on **Nature Reviews Rheumatology**.

The COVID-19 pandemic has brought many challenges to the already vulnerable communities of patients with rare connective tissue diseases (rCTDs). The aim of this paper, authored by ERN ReCONNET HCP members and ePAG representatives, along with members of Directorate-General for Health and Food Safety (DG SANTE) and Scuola Superiore Sant'Anna, is to highlight that many of these challenges can be translated into positive lessons to be applied in the post-COVID era.

More info

ERN ReCONNET Study on COVID-19 Vaccination in Rare and

Complex Connective Tissue Disease (VACCINATE)

ERN ReCONNET launched VACCINATE, a 30 months, multicentre, prospective observational study on adult (>18 years) patients with a diagnosis of rare and complex connective tissue diseases who will be given the vaccine during the period from January 2021 and January 2022.

This is an observational study aimed at gathering sufficient number of cases of rCTDs patients who will receive COVID-19 vaccination that will help in better understanding of both safety and efficacy of the vaccine in this population. The study will be promoted both in ERN ReCONNET Full Members and Affiliated Partners as well as in other centres treating and managing rare and complex connective tissue diseases.

More info

CPMS National Hubs

ERN ReCONNET launched the CPMS National Hubs. The National Hub 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.

Systemic Sclerosis Lay Versions

Lay versions are an adaptation of the original documents (recommendations, clinical practice guidelines, etc.) into an English-lay version, in order to facilitate the patients' access to information about their disease and thank to this to make well-informed decision about their health.

This lay version is dedicated to Systemic Sclerosis and it was developed by the ERN ReCONNET Systemic Sclerosis Disease Coordinators Vanessa Smith and Marco Matucci Cerinic, ePAG representative Ilaria Galetti and the ERN ReCONNET Team on the basis of the paper "Systemic Sclerosis state of the art on clinical practice guidelines".

TogethERN ReCONNET
kick-off meeting

The TogethERN ReCONNET kick-off meeting has been held on 8th March 2021. TogethERN ReCONNET, the European Registry Infrastructure for data harmonization in rCTDs, aims at integrating all existing and newly developed registries on rCTDs across Europe and providing a sufficient number of cases that will help in better understanding the natural course of the diseases, characterizing diseases in the early phases, mapping disease history, identifying different

disease phenotypes and distinguishing predictive variables for disease outcomes.

Assessment of ERN ReCONNET new applicants: next steps

The **Independent Assessment Body** has started the new Assessment phase that will include audits and document review of the Applicants.

EJP RD calls

ERN research mobility fellowships

The Research Mobility Fellowships is open from **March 15th** to **April 26th**.
The call aims to support PhD students, Postdocs and medical doctors in training to undertake scientific visits fostering specialist research training outside their countries of residence.

More info

Networking support scheme call

The aims of this call is to encourage sharing of knowledge on rare diseases and rare cancers of HCPs, researchers and patients, and to enable or increase the participation of usually underrepresented countries in Europe in new and existing research networks.

More info

Meetings and congresses

EULAR 2021 will be held virtually

EULAR has decided to hold the European Congress of Rheumatology 2021 virtually again to protect everyone's health and safety.

More info

RARE DISEASE DAY 2021

On Rare Disease Day 2021, ERN ReCONNET illuminated the Leaning Tower of Pisa and the Logge dei Banchi Palace.

More info

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

More info

ERN ReCONNET IT Services

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

More info

On our **website** you will find all the news updated and much more about our network.

Website

SOCIAL MEDIA CHANNELS

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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