



ERN ReCONNET Newsletter

Issue n. 13
June 2021

ERN ReCONNET Expert Panel on Clinical Practice Guidelines and Clinical–Decision Making Tools



The European Commission has launched a new programme for ERNs dedicated to Clinical practice Guidelines. Each ERN is asked to identify an **Expert Panel** on Clinical Practice Guidelines and Clinical–Decision Making Tools (CPGs & CDSTs). The main aim of this Expert Panel is to be in charge of the development, appraisal and implementation of each specific CPGs & CDSTs at ERN level.

ERN ReCONNET has identified the members of the Expert Panels:

ERN Clinical Experts: Laurent Arnaud, Benjamin Chaigne, Laura Damian, Luca Iaccarino, Alain Meyer, Cristina Pamfil, Vasco Romao, Vanessa Smith, Alberto Sulli, Chiara Tani

ERN Patient representatives: Ilaria Galetti

ERN Coordinator and designated contact point: Marta Mosca, Rosaria Talarico

External Members: George Bertsias, Alessandra Bortoluzzi, Annamaria Iagnocco, Carlo Alberto Scirè, Hervè Devillier

TogethERN ReCONNET

Mapping of existing Registries



TogethERN ReCONNET is the European Registry Infrastructure for data harmonization in rare and complex connective tissue and musculoskeletal diseases (rCTDs).

TogethERN ReCONNET is currently **mapping all existing Registries** on rCTDs (international, national, regional, etc) and is currently asking clinicians, researchers, experts and patients' representatives active in the rCTDs field to support this activity by completing a survey.

The aim of the survey is to collect the most relevant information related to the existing Registries dedicated to rCTDs. We would be very thankful if you could please answer to the questions and contribute to this initiative.

Partecipate in the survey

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.

The study received the approval of the Italian National Ethic Committee (INMI Lazzaro Spallanzani, Rome).

If you want to join us, send an email to ern.reconnet@ao-pisa.toscana.it

[More info](#)

ERN ReCONNET Short-Term Mobility Programme Policy



The European Commission launched and supported the **ERN Short-Term Mobility and Exchange Programme**.

The aim of the ERN Short-Term Exchange Programme 2021-2022 is to enhance knowledge sharing and stimulating collaboration between health care professionals in ERNs and strengthen capacities and organisation of the ERNs. [Ecorys Ltd](#) will support all European Reference Networks with the

design and logistics of the Exchange Programme of the European Commission. In the coming two years, three editions of exchanges will take place. The first edition will start in 2021. Ecorys Ltd will support all European Reference Networks with the design and logistics of the Exchange Programme of the European Commission.

The Short-Term exchange programme is meant to meet goals and strengthen capacity on the network level. It is not meant for research nor for individual development (though this may be a secondary effect of the exchange programme). The thematic scope includes medical practice and skills but also organisational aspects of a network. Specific priorities that the ReCONNET will address, are:

- Sharing of clinical and organisational knowledge on rCTDs aimed at improving care;
- Education and training of healthcare professionals on rCTDs;
- Sharing good practices on rCTDs;
- Support of patient empowerment and education on rCTDs.

As defined by the Commission, each ERN will decide which proposals will be rewarded, in consultation with the EC and Ecorys. Exchange visits will address the above-mentioned priorities.

[More info](#)

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.

ERN ReCONNET Systemic Sclerosis Disease Coordinators **Vanessa Smith** and **Marco Matucci Cerinic**, ePAG representative Ilaria Galetti and the ERN ReCONNET Team developed the lay version dedicated to Systemic Sclerosis, on the basis of the paper "[Systemic Sclerosis: state of the art on clinical practice guidelines](#)".

The Systemic Lupus Erythematosus Lay Versions is currently under development.

Systemic Sclerosis Lay Versions

ERICA kick-off meeting



On Thursday 27th May 2021 and Friday 28th May 2021 the virtual kick-off meeting and the first General Assembly of the **European Rare Disease Research Coordination and Support Action** (ERICA) took place.

The aim of ERICA, in which all 24 ERNs take part, is to build on the strength of the individual ERNs and create a platform that integrates all ERNs research and innovation capacity.

ERICA will strengthen research and innovation capacity by the integration of ERN research activities, outreach to European research infrastructures to synergistically increase impact and innovation. This will result in efficient access and safe therapies for the benefit of patients suffering from rare diseases and complex conditions.

[More info](#)

Past webinars



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

Past webinars

Courses and surveys



International Summer School on Rare Disease Registries and FAIRification of Data

The international course “International Summer School on Rare Disease Registries and FAIRification of Data”, **September 27 – October 1, 2021**, ISS, Rome will be held online.

This course (free of charge) is a part of a series of training activities proposed by [EJP-RD](#), and is made up of 5 days of training organized by Istituto Superiore di Sanità in close collaboration with EJP-RD task partners.

Registration deadline: **11 July**

[Register online](#)



Pregnancy: stories of patients that are living with rare and complex rheumatic diseases

The Reproduction, Pregnancy and Rheumatic diseases Working Group (**RheumaPreg**) is collecting the experiences of clinicians and patients that are living with rare and complex rheumatic diseases.

RheumaPreg is collecting anonymous stories of patients that had one or more pregnancies in an on-line platform where patients can express their point of view, perceptions and tell their story regarding their care and their journey during Pregnancy.

[Participate](#)



Open public consultation on Medicines for children and rare diseases

The European Commission has launched an **Open public consultation** on the revision of the legislation on medicines for children and rare diseases (medicines for special populations). This is an important step in the process of assessing the impact of possible amendments to EU rules for these medical areas which builds on the recent evaluation published in summer 2020. This evaluation showed that the regulations have stimulated research and development of medicines to treat rare diseases and of medicines for children. However, while 95% of rare diseases still have no treatment option, the [evaluation](#) also revealed shortcomings in the current system concerning in particular the development of medicines in areas of high unmet need for patients and their accessibility to all EU patients across the Member States. Interested parties, in particular health professionals, patients, doctors, academia, researchers, pharmaceutical industry and citizens are invited to share their views via a questionnaire, **until 30 July**, to help explore several options in view of the revision of the legislation.

[More info](#)

EURORDIS Black Pearl Awards



The **EURORDIS Black Pearl Awards** are presented to individuals, organisations and companies who dedicate their lives to making a difference for the rare disease community.

Despite important advances, the rare disease community continues to face enormous challenges. The work and achievements of the awardees are of paramount importance to improving lives and finding cures for people living with a rare disease.

The eleventh edition of the Awards will take place on Tuesday, 8th February 2022 from 18:15 until 19:30 CET and will bring together persons living with a rare disease, patient advocates, policy makers, scientists, healthcare professionals, industry representatives, and more.

[More info](#)

EULAR 2021



ERN ReCONNECT participated to the European Congress of Rheumatology 2021 with a virtual booth.

[More info](#)

CPMS National Hubs



ERN ReCONNECT 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 ReCONNECT.

[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 ReCONNECT IT Services



You can find all informations about the **ERN ReCONNECT IT Services** on the ERN ReCONNECT 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



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



Follow us on
Twitter

Visit our
Website

Subscribe to
our YouTube
Channel



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



Email sent to [mail]

Unsubscribe

