



ERN ReCONNET Newsletter

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ERN ReCONNET Supplement *Rare inside rare*



ERN ReCONNET will soon publish a Supplement dedicated to the rarest connective tissue diseases (CTDs) and to the rarest aspects of rare and complex connective tissue diseases. The main aim of the Supplement is to share the knowledge of the ERN ReCONNET Network on these aspects rarest CTDs and on the rarest aspects of rare and complex CTDs.

The Supplement will include also a network article summarising the 5-years work of ERN ReCONNET.

ERN ReCONNET Exchange Programme



The first call for applications to the ERN ReCONNET Short-Term Mobility and Exchange Programme is over.

If you are a Health professional working in the ERN ReCONNET centres or an ERN ReCONNET ePAG, you can

apply for the next two editions in 2022 (next deadlines will be available soon).

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](#)

FAI²R videos on ERN ReCONNET YouTube channel



Discover the new playlist "FAI²R" on our YouTube channel, which will contain english videos developed by the French Healthcare Network for Auto-immune and auto-inflammatory rare diseases ([Filière de santé des maladies auto-immunes et auto-inflammatoires rares](#)) on the topics of ERN ReCONNET.

These are the first three videos:

- Dr. Nicole Fabien, Strategy and diagnosis of autoantibodies
- Dr. François Chasset, Advances in the treatment of cutaneous lupus erythematosus
- Prof. Jérôme De Seze, Neurological manifestations of Sjögren Syndrome

Videos playlist

ERN ReCONNET Study on COVID-19 Vaccination in Rare and Complex Connective Tissue Disease (VACCINATE)

VACCINATE, the ERN ReCONNET 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, is still ongoing.

This observational study is 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 has been 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.

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

[More info](#)

TogethERN ReCONNET

Mapping of existing Registries



The [TogethERN ReCONNET](#) survey dedicated to mapping **mapping all existing Registries** on rare and complex connective tissue and musculoskeletal diseases (rCTDs).

The aim of the survey was to collect the most relevant information related to the existing Registries dedicated to rCTDs. Survey results will be available soon.

EJP RD Funding Opportunities



ERN Research Training Workshops

The goal of the workshops is to train **researchers and clinicians affiliated to ERN Full Members or Affiliated Partners** in relevant topics on research in rare diseases. Training themes may include innovative research methodologies, diagnostic research methodologies, interdisciplinary treatment approaches, such as gene therapy and transplantation, etc. Moreover, the workshops will be aiming to provide a cross-ERN added value.

The workshops will be delivered as **two-day events**. Topics can be proposed by clinicians/investigators affiliated to ERN-institutions or EJP RD beneficiaries.

The call is open from **6 September** until **4 October 2021**

[More info](#)



Networking Support Scheme

The **first aim** of the **Networking Support Scheme** is 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.

The **second aim** of the **Networking Support Scheme** is 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. Next deadline **2/12/2021 at 14.00 (CET)**

Italian ERNs online event

Points consider to the rare diseases community



In February 2021, to mark [World Rare Disease Day](#), ERN ReCONNET, [MetabERN](#), [ERN BOND](#), the Federation of Associations of People with Rare Diseases in Italy ([Uniamo FIMR Onlus](#)), the Italian National Institute of Health ([Istituto Superiore di Sanità](#)) and [ePAG Italia](#) organised an event involving italian ERN coordinators, network members, patient representatives, patients, clinicians, etc.

It was a crucial opportunity to share **good practices** implemented by the ERNs (in terms of patient involvement, care pathways, education and training, clinical trials and research and guidelines), but above all to listen to the patients' point of view.

The next step was to organise **five internal workshops** during 2021 to discuss the perspectives and concrete actions to be put in place in view of the integration of ERNs in the italian national health system, focusing on the needs of the rare disease community. It is precisely the excellence of the experience of ERNs and the fundamental role of increasingly aware and experienced patients that can provide useful guidance to all stakeholders.

For this reason, the Organising Committee organised a final online event on **30th November 2021** from **4pm** to **6pm** CET, which will be attended by rare disease coordinators of italian regions, patients' associations, hospital managers, health directors/chief medical officers, Rare Disease Registry and

rare disease centres managers, political representatives, pharmaceutical industries, general practitioners, etc.

The event will be visible on the Zoom platform after registration at this [link](#) or live on the [ERN ReCONNET YouTube channel](#).

Register to attend the event



New sections on ERN ReCONNET website

On our [website](#) you will find new sections on "Activities" label. We are preparing for major changes... stay tuned!

[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

[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.

[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](#)

SOCIAL MEDIA CHANNELS



ERN ReCONNET YouTube Channel and Twitter page

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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



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