



ERN ReCONNET Newsletter

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Clinical Practice Guidelines: a new publication by ERN ReCONNET



ERN ReCONNET developed two surveys to map the adherence to rare and complex connective tissue and musculoskeletal diseases (rCTDs) clinical practice guidelines (CPGs) among healthcare providers and to assess the knowledge and awareness of CPGs for their diseases among patients, family members and caregivers. According to the results of the surveys, ERN ReCONNET is addressing the main issues identified, promoting practical actions for the local adaptation of CPGs across Europe, improving their routine clinical use and increasing the awareness on CPGs among rCTDs patients, family members and caregivers.

[Read more](#)

What you need to know.
a new section on ERN ReCONNET
website dedicated to patients



The **ERN ReCONNET ePAGs** developed a new section of the website called "What you need to know". The section provides information and resources on specific topics of interest to patients. The first two topics are **pregnancy** and **clinical practice guidelines**.

In these pages you will find webinars made by patients, infographics resulting from these webinars, links and useful information.

What you need to know

Assessment of ERN ReCONNET new applicants: next steps



The ERN ReCONNET Board of Network, after a very careful review, provided the draft opinions on all the membership applications. Now each applicant has one month to review the comments received and to revise its application.

After the final review by the Board of Network, the next step will be the Validation of the Application by the Independent Assessment Body.



Info on 2019 Call for membership

ERN ReCONNECT webinars



Seven new ERN ReCONNECT webinars have been released and are available on our [YouTube channel](#):

- Giuseppe **Turchetti**, [Economic evaluation techniques in healthcare: a practical toolkit](#);
- Ilaria **Galetti** and Rosaria **Talarico**, [Clinical practice guidelines: what do you need to know](#);
- Laurent **Arnaud**, [Drug-induced lupus. From historical case reports to big data](#);
- Maurizio **Cutolo**, [The Rheumatological point of view of EDS Syndromes: Articular manifestations](#);
- Marco **Castori**, [Hypermobile EDS and Hypermobility Spectrum Disorders what is the difference](#).

Next webinars:

Fransiska **Malfait** and Alberto **Sulli**, Skin manifestations in EDS: what are they and how to manage them (6 October 2020, 15:00 CET)

Leema **Robert** and Fransiska **Malfait**, Cardiovascular aspects of EDS – Joint ERN ReCONNECT and VASCERN webinar (20 November 2020, 14:00 CET)

[More webinars](#)

EJP RD trainings



Research Training Workshop call

The goal of the workshops is to train researchers and clinicians affiliated to **ERN Full Members** or **ERN Affiliated Partners** in relevant topics on rare diseases research, such as innovative research methodologies, diagnostic research methodologies, interdisciplinary treatment approaches (e.g. gene therapy and transplantation), etc. Registration deadline **12 October 2020**.

[More info](#)

Research Mobility Fellowships

The call for Research Mobility Fellowships aims to financially support PhD students and medical doctors in training affiliated to **ERN Full Members** or **ERN Affiliated Partners** to undertake short scientific visits (secondments) fostering specialist research training outside their countries of residence and within one of the ERN host institutions. Registration is open from **1 October 2020**.

[More info](#)

COVID-19 dedicated section on ERN ReCONNET website



The ERN ReCONNET COVID-19 dedicated section is constantly being updated with all statements from organisations and entities related to ERN ReCONNET and people with connective tissue and musculoskeletal diseases.

[Updates on COVID-19](#)

COVID-19

Clinical Management Support System



The European Commission launched the **COVID-19 Clinical Management Support System** with the aim to support clinicians in hospitals that are currently facing the coronavirus emergency all over Europe.

Based on the experience with the [European Reference Networks](#), the initiative helps to create rapid connections across Europe among the hospitals indicated by the Member States as reference centres for COVID-19. Clinicians can rely on a dedicated helpdesk managed by [DG SANTE](#) to set up web conferences and exchange with their peers in Europe on possible treatments, and on how to handle severe and complex cases.

For joining the system, you need to register [here](#).

More info on COVID-19 CMSS

Meetings and congresses



Ehlers–Danlos Society ECHO Summit 2020

EDS ECHO Summit will be held **online** on October 2–3, 2020.

[More info](#)



ACR 2020 meeting goes virtual

The ACR annual meeting will be held **online** on November 5–9

[More info](#)



Italian Society of Rheumatology Congress 2020

The SIR annual meeting will be held **online** on November 25–28

[More info](#)

ERN ReCONNET plenary meeting



The next **ERN ReCONNET plenary meeting** has been postponed to **2021**

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



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



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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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