



ERN ReCONNET Newsletter

Issue n. 9
June 2020

The new official EU Health video on European Reference Networks



The official **EU Health** video with the ERN ReCONNET ePAG representative **Ilaria Galetti** testifying on the work undertaken by the European Reference Networks for and with the patients.

Watch

The official **EU Health** video with the ERN ReCONNET Coordinator prof. **Marta Mosca** who illustrate what the activities and the added value of the European Reference Networks are.

Watch

ERN ReCONNET ePAGs translated the Fai2R recommendations



ERN ReCONNET has endorsed the **Filière de Santé des Maladies Auto-immunes et Auto-inflammatoires Rares (Fai²R) recommendations** for treatment of patients with autoimmune or auto-inflammatory diseases during COVID-19 pandemic.

Thanks to the commitment of ERN ReCONNET **European patients advocacy groups**, the recommendations have been translated into 16 languages, and adapted by Fai²R. The same has been done with the suggestions on **How to live better** during the containment period.

ERN ReCONNET has realised some infographics based on the recommendations.

In the meantime, the Filière is constantly updating its [recommendations](#).

[Read the recommendations](#)

Alain Cornet treasurer of EURORDIS



Congratulations to **Alain Cornet**, general secretary of [Lupus Europe](#) and ePAG representative of ERN ReCONNET, elected treasurer of [EURORDIS](#), the European Organisation for Rare Diseases.



EURORDIS Good Practice: Building a National ePAG group (ePAG Italy)

A group of Italian ePAGs and representatives of the Italian Rare Diseases Alliance, decided to join forces and to establish a national group of ePAG Advocates. The main aim of **ePAG Italy** is to create an active group of patients' representatives that could contribute to the Integration of ERNs into the Italian Health System. [Here](#) you can find the recording of the webinar presenting the good practice.

[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

Assessment of ERN ReCONNET new applicants suspended



The examination of membership applications for existing ERNs is suspended **from 1 April 2020 to 31 August 2020**. Due to the outbreak of the COVID-19 pandemic, the efforts of healthcare providers and health professionals in the Union are fully devoted to addressing the ongoing public health crisis. As a consequence, the Commission decided to suspend the on-going evaluation process to allow health care providers to fully dedicate to the management of the sanitaria crisis, and at the same time preserving the evaluation of the applications from disruptive consequences. The examination process will resume on **1 September 2020** and the suspended time limits will continue running from that date.

[Read more](#)



European Commission webinar on COVID-19 and Rare Connective Tissue and Musculoskeletal diseases and conditions

In the context of the “COVID-19 Clinical Management Support System” launched by the European Commission, [DG SANTE](#) organises a series of webinars to support clinicians and other healthcare professionals at the frontline of the care of COVID-19 patients. These webinars bring the expertise and recommendations of several experts from the

24 ERNs in the management of challenging cases of patients suffering at the same time of COVID-19 and a rare or complex disease or conditions.

The purpose of the [webinar](#), held on 15th June 2020, is to provide an overview of how the Covid-19 is impacting patients affected by rare and complex connective tissue and musculoskeletal diseases and conditions.

The topic has been addressed from the perspective of a patient by **Ilaria Galetti**, Patient Representative of the European Federation for Systemic Sclerosis, ERN ReCONNECT ePAG, and from the perspective of a health professional and expert, Prof. **Marta Mosca**, Azienda Ospedaliero Universitaria Pisana in Italy, Professor of Rheumatology and Chief of the Rheumatology Unit, ERN ReCONNECT Coordinator.

Watch the webinar

ERN ReCONNECT webinars



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

- Laurent **Arnaud**, [Relapsing Polychondritis: 2020 highlights](#);
- Monika **Østensen**, [Drug toxicity during pregnancy and lactation](#);
- Giuseppe **Turchetti**, [Health Economics: Why, When, How](#);
- Maurizio **Cutolo**, [Sex hormones and COVID-19: how is the game?](#);
- Charissa **Frank** and Fransiska **Malfait**, [EDS syndrome: a disorder with many faces](#);
- Victoria **Werth**, [Treatment of cutaneous manifestations in SLE](#)
- Silvia **Aguilera** and Marta **Mosca**, [Pregnancy in rare and complex connective tissue and musculoskeletal diseases](#)

Next webinars:

Maurizio **Cutolo**, The Rheumatological point of view of EDS Syndromes: Articular manifestations (24 July 2020, 14:00 CET)

Marco **Castori**, Hypermobility EDS and Hypermobility Spectrum Disorders: what is the difference? (10 September 2020, 15:00 CET)

Giuseppe **Turchetti**, Health Economics and rare diseases (16 September 2020, 14:30 CET)

EJP RD trainings



International Summer School on Rare Diseases Registries and FAIRification of Data

This on line training will be held on two modules (**28–30 September** and **1–2 October**). Deadline for registration: **19 July 2020**.

[More info](#)

Quality assurance, variant interpretation and data management in the NGS diagnostic era

The training will be held in Istanbul (**12–14 October**). Deadline for registration: **20 July 2020**. A mitigation plan is in place due to COVID-19.

[More info](#)



The [European Medicines Agency](#) (EMA) will waive all fees for scientific advice for academia developing **orphan medicines** to further encourage the development of treatments for rare diseases.

EMA decided to include academia in the list of organisations eligible for free protocol assistance as of 19 June 2020.

Eligible applicants will include public or private **higher education establishments** awarding academic degrees, public or private **non-profit research organisations** whose primary mission is to pursue research, and **international**

European interest organisations. These entities should not be financed or managed by private for-profit organisations in the pharmaceutical sector or have concluded any agreement with pharmaceutical companies concerning their sponsorship or participation in a specific research project for which a fee exemption is sought.

[More info](#)

Meetings and congresses



Systemic Sclerosis World Congress

The 6th SSc World Congress will be held **online** on July 12–14, 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

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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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