ERN ReCONNET Newsletter

Issue n. 8
March 2020

COVID-19 is a disease caused by a new type of coronavirus (SARS-CoV-2), first identified in December 2019 in the Chinese municipality of Wuhan.
At the end of February 2020, Italy reported a significant increase of COVID-19 cases concentrated in the northern regions of the country. By March 2020, all EU member states had reported quickly increasing COVID-19 cases.
The current COVID-19 pandemic is a rapidly evolving situation and we will use a dedicated page on our website to update you on all statements from organisations and entities related to ERN ReCONNET and people with connective tissue and musculoskeletal diseases.

Updates on COVID-19

European Commission launched the COVID-19 Clinical Management Support System

On 24 March, 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 will help 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.

More info on COVID-19 CMSS

Second phase of the assessment of ERN ReCONNET new members

The assessment of the applications to join existing ERNs is entering the second phase.
The Board of the ERNs are now assessing all the eligible applications for their Network. The applications with favourable ERN decisions will be then forwarded to the Independent Assessment Body that will conduct an additional assessment. The final phase is the formal approval of each candidature by the ERN Board of Member States, which will take up to two months.
It should be emphasized that the final number of new members will only be known at the end of the whole assessment process, which is expected to be at the end of 2020 (assuming that the COVID-19 outbreak does not slow down the process).

Read more

Rare Disease Day 2020

ERN ReCONNET organised the "RareDiseases and European Reference Networks" meeting at Pisa on 22nd February 2020 as part of the [Rare Diseases Day](#) celebrations. It was an excellent opportunity for italian ERNs and patients' representatives to meet and discuss on good practices in rare diseases.

On 29th February 2020 ERN ReCONNET illuminated the Leaning Tower of Pisa with the colours and the logo of the Rare Disease Day, in order to spread public and political awareness of rare diseases all over the world through a worldwide known icon.

Read more

ERN ReCONNET webinars

Other three ERN ReCONNET webinars have been released: Guillermo Ruiz-Irastorza, [Glucocorticoids in SLE. Can they be used differently?](); Vanessa Smith, "[The Raynaud's phenomenon]()" and Maurizio Cutolo, "[Don't neglect a correct nutrition in rheumatic diseases]()".
New webinars both for healthcare professionals and patients will be announced soon.

European Joint Programme on Rare Diseases (EJP RD)

Biomedical Research Training Workshop

This on line training workshop week will be held on 11-15 May at Medical University of Graz.

More info

Networking Support Scheme (NSS) is open

The applications will be collected on June 2, September 1, December 1, 2020.

More info

Meetings and congresses: COVID19 updates

Systemic Sclerosis World Congress

The 6th SSc World Congress has been postponed to July 2020.

More info

European Conference on Rare Diseases

The 10th ECRD will take place online on May 14–15, 2020.

More info

European Congress of Rheumatology

The 2020 EULAR Congress will be available online on June 3–6, 2020.

More info

ERN ReCONNET plenary meeting

The next ERN ReCONNET plenary meeting has been postponed to 2021

European Survey on Patient Education

Lupus Europe and ERN ReCONNET Patient representatives have launched a short survey to better understand how we can improve quality of life for people living with a rheumatic condition through better patient education.
Simply click on the button below, select your language, and complete the 3 minutes survey to share your input; then send the link to other patients, so that we get even more feedback.
The survey is available in english, español, français, italiano,

nederlands, português, slovenščina. If your language is missing and you are ready to help us, please contact secretariat@lupus-europe.org

Survey on ERN ReCONNET website

A short on line survey in order to collect feedback on the ERN ReCONNET website is available clicking on the button below. It takes only five minutes to complete, and your help is truly appreciated. We really need your opinion and suggestions on satisfaction and updates.

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.
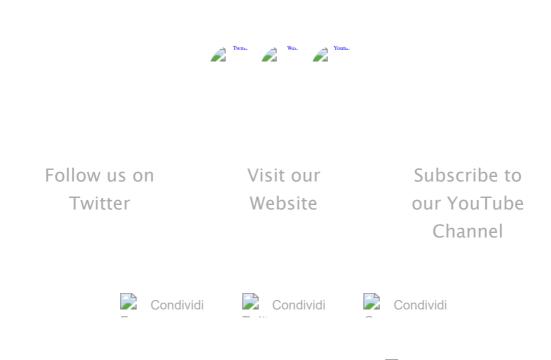For more information on how to access the CPMS and how to request a virtual consultation, please contact us at:
helpdesk.reconnet@ao-pisa.toscana.it

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](#)