ERN ReCONNET Newsletter

Issue n. 1
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NEWS

Two new ePAG Advocates in the ERN ReCONNET: welcome to Ana Vieira and Alain Cornet!

Ana Vieira, from Núcleo Síndrome de Sjögren of [Liga Portuguesa Contra as Doenças Reumáticas](#) (LPCDR, Portuguese league against rheumatic diseases), will represent the Complex Connective Tissue patients in the Steering Committee.

Alain Cornet, General Secretary of [Lupus Europe](#), will follow the representation of Systemic Lupus Erythematosus within ERN ReCONNET, as Sara Badreh has resigned from her role of patient representative.

Welcome to Ana and Alain who will be actively involved in the ERN ReCONNET activities!

A summary of our dissemination activities

From March to June ERN ReCONNET took part in six conferences and workshops, disseminating the project with booths and presentations.

1. Milan, 17th March 2018: National Conference "ScleroNet Al servizio dell'ammalato". Joint presentation of ERN ReCONNET by Ilaria Galetti, Marco Matucci Cerinic and Diana Marinello.

2. Genoa, 12th–14th April 2018: XVII Mediterranean Congress of Rheumatology. Marta Mosca's presentation on ERN ReCONNET and ERN ReCONNET booth.

3. Wien, 10th–12th May 2018: 9th European Conference on Rare Diseases & Orphan Products. ERNs booth and poster presentation.

4. Rome, 12th May 2018: XXI National Conference Italian Rheumathologists College. Ilaria Galetti's presentation on ERN ReCONNET.

5. London, 29th–30th May 2018: RD-ACTION / EMA / DG SANTE workshop "How European Reference Networks can add value to clinical research". Joint partecipation by Ilaria Galetti, Alain Cornet, Simone Barsotti.

6. Amsterdam, 13th–16th June 2018: EULAR 2018 Annual European Congress of Rheumatology. ERN ReCONNET booth at the EULAR Village

NEXT MEETINGS

ERN ReCONNET Webconferences

Two webconferences will take place in July, 17th from 14:00 to 15:00 CET and in July, 23th from 15:00 to 16:00 CET.

The webconferences, regarding the update of the activities and deadlines, will be be a good opportunity to share comments, experiences and proposals for our work.

International Symposium of the Ehlers-Danlos Syndromes

Ghent, Belgium, 26th-29th September 2018.

The [International Symposium on the Ehlers-Danlos Syndromes](#) (EDS) is a state-of-the-art meeting in which new research on clinical advances and the molecular and pathogenic mechanisms underlying EDS and related syndromes is discussed

ERN ReCONNET Meeting

The next ERN ReCONNET meeting will take place on 13th - 14th January 2019 in Pisa.

The meeting will be dedicated to the following activities:

• WPs conclusions, disease coordinators reports and next steps planning

• Steering committee, ePAGs and ESAB meetings and next steps planning

• Discussion on activities for the third year (2019) of the project

WEBSITE AND CPMS

First implementation of ERN ReCONNET website

The ERN ReCONNET website has been implemented. In the home page you can now find a direct link to the Disease info page, with the description of the 10 diseases covered by the ERN ReCONNET as well as a list of useful references. A direct link to the Clinical Patient Management System and to the ERN Collaborative platform is also available on the bottom bar.

In addition, the photos of the main pages have also been updated.

Join the 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.
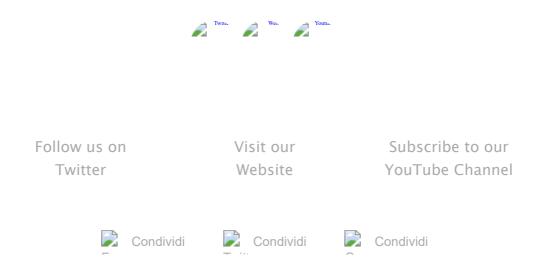
The CPMS is a secure Software as a Service (SaaS) that enables health professionals to enrol patients using comprehensive data models. Health professionals can use the CPMS to collaborate actively and share patient within and across ERNs.

For more information on the CPMS, please contact us at: ern.reconnet@ao-pisa.toscana.it

ERN ReCONNET YouTube Channel

Subscribe to the ERN ReCONNET official [YouTube channel](#)!

Here you will find videos, tutorials, and many other contents upon the European Reference Network on Rare and Complex Connective Tissue and Musculoskeletal Diseases, the European Reference Networks and other initiatives.

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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](#)