



ERN ReCONNET Newsletter

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Welcome to the new APS ePAG
Silvia Aguilera



Silvia Aguilera is the new ERN ReCONNET ePAG for the [Antiphospholipid Syndrome](#). Silvia is part of the board of the [Asociación Española Síndrome Antifosfolipídico](#) (Spanish Antiphospholipidic Syndrome Association), where she is in charge of international relations, website content editor and part of the social media managing team. Welcome on board!

Our ePAGs experience chosen by EURORDIS as best practice



The patients' involvement in identifying unmet needs on [Clinical practice guidelines](#) has been recognized as **best practice** by [Eurordis](#).

[Read more](#)

EULAR Congress
Madrid, 12–15 June 2019



[EULAR](#) (the European League Against Rheumatism) has taken its [Annual Scientific Congress](#) in Madrid, Spain, from 12th to 15th June 2019. The annual EULAR Congress comprise **the major event in the calendar of world rheumatology.**



ERN ReCONNET was present at EULAR 2019 with a **dedicated booth**, that allowed not only to welcome members of the ERN, but also to receive patients, patient representatives and clinicians interested in joining the network.



The Congress also provided the opportunity for a **meeting** between ePAGs, Health Care Providers, Disease Coordinators and Steering Committee members. During the Meeting, all the disease coordinators were confirmed with an open vote.



EJP–RD 1st Pillar2 Annual Retreat meeting



The 1st EJP–RD Pillar2 Annual Retreat meeting has been held in Rome (Italy) at [Istituto Superiore di Sanità](#), from 22 to 24 June 2019.

52 people were present among Pillar 2 WP and task leaders and ERNs representatives (Dr. Rosaria Talarico for ERN ReCONNET).

The next EJP–RD Pillar 2 Annual Retreat meeting will take place at Istituto Superiore di Sanità, from 4th to 6th May 2020.

[Read more](#)

8th ERN Coordinators Meeting (Brussels, 24th June 2019)



The 8th ERNs Coordinators Meeting has been held last 24th June in Brussels. The meeting provided the opportunity for the ERN Coordinators to discuss with the European Commission on the Enlargement of the Networks and on the Designation of Affiliated Partners.

10th World Scleroderma Day (Rome, 27th June 2019)



On occasion of the 10th World Scleroderma Day, [Fesca](#) (Federation of European Scleroderma Associations) and [World Scleroderma Foundation](#) organised a [conference](#) at the Italian Parliament Library. [Ilaria Galetti](#) (ERN ReCONNET ePAG for Systemic Sclerosis) presented the patients' involvement in the network; network coordinator [Marta Mosca](#) outlined main results and next objectives of the ERN ReCONNET; ESAB member [Domenica Taruscio](#) highlighted the sustainability issue of the ERNs.

EU call for proposals on *Rare disease registries for the European Reference Networks*



The Consumers, Health, Agriculture and Food Executive Agency (CHAFAEA) has published the call for **Rare disease registries for the European Reference Networks**.

The proposed action aims to support the development of rare disease registries for the European Reference Networks not yet receiving grants for registries.

Patient registries and databases constitute **key instruments** to develop clinical research in the field of rare diseases, to improve patient care and healthcare planning. They are the best way of pooling data to achieve a sufficient sample size for epidemiological and/or clinical research. Registries serve as a recruitment tool for the launch of studies focusing on disease etiology, pathogenesis, diagnosis or therapy.

[Read more](#)

New ERN information flyers released by ERN ReCONNET



During the European Congress of Rheumatology, ERN ReCONNET has released **a new version** of the *Patients' involvement* flyer, of the *How to get involved* flyer and of the *CPMS* flyer (available and downloadable [here](#)).

[Read more](#)

ERN ReCONNECT Supplement on RMD Open



The ERN ReCONNECT has published on RMD Open (BMJ) a supplement dedicated to the [State of the art of Clinical Practice Guidelines in Rare and Complex Connective Tissue Diseases](#).

The Supplement presents a short report on the first year of activity of the ERN ReCONNECT, ten reviews on clinical practice guidelines of the Diseases covered by the ERN ReCONNECT project, and a report on rCTDS Health Economics. **All articles are available and downloadable**

[Read more](#)

WEBSITE

Update of the ERN ReCONNECT website



Visit our [website](#) to see the new contents and to stay tuned for more updates!

SOCIAL MEDIA CHANNELS



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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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