



ERN ReCONNET Newsletter

Issue n. 7
December 2019

**Season's Greetings and
a very Happy New Year
from ERN ReCONNET**



ERN ReCONNET ePAGs activities



October 2019:
**Vera Guimarães and Ana
Vieira** at the [EULAR](#) Patient
Research Partners (PRPs)
biannual meeting in Prague

[More info](#)

**Silvia Aguilera, Alain Cornet,
Charissa Frank, Ilaria Galetti**
at the 1st Expert Panel
Consensus Meeting on
Patients' Pathways in Pisa

[More info](#)



November 2019:
Alain Cornet at the 1st
[European Patients'
Forum](#) Congress in Brussels

[More info](#)



Ilaria Galetti at [EURORDIS](#)
Leadership School on
Healthcare & Research face-
to-face training in Barcelona

[More info](#)

New members to join existing ERNs soon



The call for new members to join existing ERNs is now closed. ERN ReCONNECT received 38 applications from 14 countries.

The assessment of the application consists of several steps. First, the European Commission will conduct an **eligibility check** of all submitted applications. Then, the Board of the ERNs will have to assess 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**.

The geographical coverage of the ERNs already underwent a

first phase of enlargement earlier this year, with the inclusion of "[Affiliated partners](#)" between June and November 2019. Designation process concluded within the launch of the ERN 2019 call. 10 Member States designated 14 Affiliated Partners for ERN ReCONNET.

[Read more](#)



Expert Panel Consensus Meeting on Patient Pathways



The **Expert Panel Consensus Meeting on Patients Pathways** was held in Pisa on 27th and 28th October 2019. The meeting outlined the current practice in the organization of rCTD care in the ERN ReCONNET centres and the patients' perspective on their pathway, establishing the basis for the implementation of the pathways for all the diseases covered by ERN ReCONNET.



During the Expert Panel Consensus Meeting on Patients Pathways the book "**ERN ReCONNET Systemic Sclerosis Patient's Stories**" was presented. This is the result of the collection of stories through a questionnaire held in Autumn 2019 among over 200 European Scleroderma patients.

ERN ReCONNET webinars



The first two ERN ReCONNET webinars have been released:
Vanessa Smith "[Microcirculation \(capillaroscopy\) and SLE](#)"
and Maurizio Cutolo, "[The real roles of Vitamin D in
Connective Tissue Diseases](#)".

New webinars both for healthcare professionals and patients
will be announced soon.

European Joint Programme on Rare Diseases (EJP RD) calls



Joint
Transnational
Call 2020
(JTC2020)

The deadline for
registration and
submission of
pre-proposals is
the 18th of
February 2020

[More info](#)

Clinical Trials
Methodology
Demonstration
Projects Call

The 2020
submission
deadlines are:
March 15 1-pager
May 15 full
proposals

[More info](#)

Networking
Support
Scheme (NSS)
is open

The applications
will be collected
on **March 3, June
2, September 1,
December 1,**
2020.

[More info](#)

International meetings



ACR 2019

On November 2019 ERN ReCONNET was present at the **American College of Rheumatology Annual Meeting** in Atlanta with a dedicated [booth](#) in the Exhibit Hall of Georgia World Congress Center.

[More info](#)

ERN–CG meeting

The ERN ReCONNET Team was at the **9th Meeting of the European Reference Networks Coordinators Group** (ERN–CG). Main topics were Affiliated partners, New members call, diseases coverage, and research.

[More info](#)



SIR 2019

On November 2019 ERN ReCONNET was present at the **56th Italian Society of Rheumatology Congress...**

[More info](#)

Lupus Europe

... and participated to the **Lupus Europe 30th Annual Convention "Education to empower"**.

[More info](#)

Next meetings and congresses



Systemic Sclerosis World Congress

The 6th SSc World Congress will be held in Prague on March 5–7, 2020

[More info](#)

European Conference on Rare Diseases

The 10th ECRD that will take place in Stockholm on May 15–16, 2020.

[More info](#)

European Congress of Rheumatology

The EULAR Congress will be held in Frankfurt on 3–6 June, 2020

[More info](#)

ERN ReCONNET

plenary meeting



The next ERN ReCONNET plenary meeting will be held in Pisa, on May 11–12, 2020

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](#)

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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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