



ERN ReCONNET Newsletter

Issue n. 6
September 2019

Call for new members launched



We are pleased to inform you that the call for new members to join existing ERNs will be open from 30 of september **until 30 of November 2019.**

You will find more information on the call and access to all relevant documents in the following [link](#)

Expert Panel Consensus Meeting on Patient Pathways



The Expert Panel Consensus Meeting on Patients

Pathways will be held in Pisa on 27th and 28th October 2019. The aim of the Meeting is to get the picture of the current practice in rCTDs care organization across the different ERN ReCONNET centres and patients perspective of their pathway.

ePAG Steering Committee



The [Eurordis ePAG](#) Steering Committee was held last 20th September in Brussels. **Charissa Frank** and **Ilaria Galetti** participated as ERN ReCONNET ePAGs.

Dissemination of ERN ReCONNET



World Sjögren's Day at University Hospital of Vigo

The [University Hospital Complex of Vigo](#) (Chuvi) celebrated on 23th July the World Sjögren's Day. **Ana Vieira**, ERN ReCONNET ePAG representative and Board member of [Sjögren Europe](#), shared the patient perspective and the ERN ReCONNET experience. The event consisted of a clinical session aimed at informing patients organized by Dr. José María Pego and presented by the manager of the area, Julio García.

16th International Congress on APS at Manchester

Silvia Aguilera represented the [Spanish APS Association](#) and ERN ReCONNET at the 16th International Congress on Antiphospholipid Antibodies ([ICAPA 2019](#)) that took place in Manchester from 17 - 20 September 2019. The congress occurs every three years, focusing on many exciting and evolving topics that are of great relevance across a range of medical subspecialties including rheumatology, haematology, obstetrics and neurology.

European Joint Programme on Rare Diseases



Workshop and General Assembly at Gdańsk

ERN ReCONNET attended on September 2019 the [European Joint Programme on Rare Diseases \(EJP RD\)](#) workshop in Gdańsk on “[Rare disease perspectives in Central – Eastern Europe](#)”, twinned to the General Assembly. The main aims of this conference were to discuss challenges and opportunities of rare disease research in Central – Eastern Europe countries and areas of involvement within EJP RD for multiple stakeholders (including researchers, clinicians, authorities, and patient organizations). Presentations on rare disease

International Summer School on Registries

ERN ReCONNET attended the [International Summer School on Rare Disease Registries and FAIRification of Data](#), as a part of a series of training activities proposed by the European Joint Programme on Rare Diseases. In particular this Course is a part of WP14, which aims to organize residential training courses in different Countries on Data Management and Quality. The Course was made up of 5 days of residential training organized by [Istituto Superiore di Sanità](#) in close collaboration with, mainly, EJP RD task partners. Registries are key resources

policies, clinical research and innovation, data ecosystem, Orpha coding, biobanks, rare disease research education, European Reference Networks and other important topics have been given by the major EJP RD partners and representatives of local rare disease research communities.

in order to increase timely and accurate diagnosis, improve patients management, tailor treatments, facilitate clinical trials, support healthcare planning and speed up research.

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.

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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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