

European Joint Programme on Rare Diseases

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Orphanet Nomenclature and RD Ontologies for RD Research SPAIN TRAINING SESSION

May 3rd-12th (session 1)
May 17th (sessions 2 and 3)

Online

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Orphanet Nomenclature and Ontologies for RD Research - Spain Training - PRELIMINARY Program

Introduction:

The European Joint Programme on Rare Diseases (EJP RD) is a programme co-funded by the European Union and dedicated to improving research in the field of rare diseases. You can find more information about the project here: <https://www.ejprarediseases.org/>

One of the tasks that Orphanet has been assigned within this project consists on diffusing a training module on the Orphanet Nomenclature and Ontology for RD Research through the Orphanet Network.

General Objective of the Training: improving knowledge and [basic/advanced] skills about Orphanet nomenclature (including the ORPHAcodes) and Orphanet Rare Disease Ontology - ORDO for clinicians/researchers, and for the IT teams involved.

May 3rd- May 12th: Estimated duration 2.5 h

SESSION 1: ORPHANET NOMENCLATURE PRESENTATION

Objectives

- ENHANCE knowledge on Orphanet Nomenclature

Description

- Presentation of the webinar on Orphanet Nomenclature for RD research.
- The first session of this online course will be followed by participants in an individual basis between May 3rd and May 12th
- **Participants are expected to view all the presentations and complete a pre-training activity before attending Sessions 2 and 3 scheduled on May 17th**

Session 1 Contents

Title
Presentation: ORPHANET NOMENCLATURE Chapter 1
Presentation: ORPHANET NOMENCLATURE Chapter 2
Presentation: ORPHANET NOMENCLATURE Chapter 3

[May 17th, 2021 (morning)]: Suggested Length 2.5 h

SESSION 2: ORPHANET DATA AND HOW TO ACCESS IT PRESENTATION

Chair/co-chairs

María Elena Mateo / Virginia Corrochano - Elisa Checa - Miguel López de Heredia

Objectives

- ENHANCE knowledge on Orphanet data available and tools including the Orphanet RD Ontology (ORDO) and the ORDO-HPO ontological module (HOOM).

Description

- Presentation of the webinar on Orphanet data available for RD research and how to access it. It includes some slots to address any questions and doubts.

Session 2 Program

Time	Title	Speaker
10:00-10:10	Welcome & introduction	Francesc Palau / M ^a Elena Mateo
10:10-10:20	Icebreaker / pairing (organising teams)	M ^a Elena Mateo
10:20-10:35	Presentation 1: Session 1 summary	M ^a Elena Mateo
10:35-10:50	Session 1: Q&A	M ^a Elena Mateo
10:50-11:15	Presentation 2: ORPHANET DATA AND HOW TO ACCESS IT	M ^a Elena Mateo
11:15-11:35	Break	
11:35-12:00	Demo tools: API, ORDO and Dataviz	Videos
12:00-12:30	Questions & answers	Orphanet Management Team

[May 17th, 2021 (afternoon)]: Suggested Length 2.5 h

SESSION 3 : HANDS-ON

Chair/co-chairs

María Elena Mateo / Virginia Corrochano - Elisa Checa - Miguel López de Heredia

Objectives

- ENHANCE knowledge on Orphanet Nomenclature and Ontologies

Description

- Practical exercises

Program of the session

Time	Title	Speaker
15:00-15:15	Warm up / reminders	M ^a Elena Mateo
15:15-16:00	Practice time: HANDS-ON	M ^a Elena Mateo
16:00-16:15	Break	
16:15-17:00	Practice time: HANDS-ON	M ^a Elena Mateo
17:00-17:30	Q&A and Wrap-up	M ^a Elena Mateo

Registration

This EJP RD Training Orphanet nomenclature and RD ontologies for RD research is held Online using **Microsoft Teams (Ms Teams)**.

The registration form is available online from: <https://tinyurl.com/1miggmeg>