



**European
Reference
Network**
for rare or low prevalence
complex diseases

Network
Genetic Tumour Risk
Syndromes (ERN GENTURIS)

European Human Genetics Conference

Hybrid Conference

Vienna, Austria

JUNE 11-14, 2022

Workshop Title:	W11- European Reference Networks – More than just a wish?
Date:	Monday, June 13, 2022
Time:	14:00 - 15:30 hrs
Session type:	Live Event
Co-Organiser(s):	Carla Oliveira <i>carlaol@ipatimup.pt</i> Bárbara Rivera <i>brivera@idibell.cat</i>

PROGRAMME OVERVIEW:

A. SCOPE, AIM AND AUDIENCE OF THE WORKSHOP

SCOPE: This workshop is about European Reference Networks (ERNs), which are virtual networks involving healthcare providers across Europe. They aim to facilitate discussion on complex or rare diseases and conditions that require highly specialized treatment, and concentrated knowledge and resources.

AIM: The workshop is aimed at presenting and raising awareness about the European Reference Networks. This year the Workshop is devoted to the umbrella research infrastructure of SolveRD and the ERN GENTURIS. Examples of research collaborations and main research projects, registry infrastructures, challenges and benefits will be presented. A general discussion with the audience will occur at the end of the presentations.

AUDIENCE: Health Professionals and Scientists working in the field of Human Genetics in Europe.

B. PROGRAMME OF THE WORKSHOP

Carla Oliveira & Bárbara Rivera

Welcome

Steve Laurie, Centro Nacional de Análisis Genómico - Centre for Genomic Regulation (CNAG-CRG), Barcelona Spain
“*SOLVERD: OVERVIEW OF THE MAIN RESEARCH INITIATIVES AND OUTCOMES INVOLVING ERNS*”

Janet Vos, Radboud University Medical Center Nijmegen, The Netherlands
“*RESEARCH IN THE CONTEXT OF THE ERN GENTURIS*”

Round Table, Q&A

Carla Oliveira & Bárbara Rivera

Session closing

C. WORKSHOP LEARNING OUTCOME

Attendees will learn about:

1. The EU project SolveRD, its team, research infrastructure and outcomes.
2. An ERN-based research infrastructure and outcomes.
3. How to get involved and participate.