

FAIR Training Program 2025 (Part I)

Advancing FAIR data practices for rare
disease research

24-26 September 2025

13:30 - 17:00 CET

Organised by:
ERDERA and their associated partners

Hosted by:
World Duchenne Organization



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FAIR Training Program 2025

Online | 24-26 September 2025 | 13:30 - 17:00 CET

Learning Objectives

- To understand the value and benefits of FAIR
- To show the participants tangible examples of how to query FAIR data
- To know what is needed to get started with a FAIR-related project

Specific Aims

Upon successful completion of this course, participants will be able to:

- explain the importance of having FAIR (meta) data
- outline the process of making data FAIR
- propose a FAIRification process to their stakeholders
- describe the steps of conceptual modelling and conversion of data to machine-readable

Program Overview

Day 1: 24 September 2025 | 13:30 - 17:00 (CET)

The Why: The value and benefits of making data FAIR
Showcase (FAIR stories) with key successes & challenges

Day 2: 25 September 2025 | 13:30 - 17:00 (CET)

The What: General Overview on the FAIR Guiding Principles and FAIR Project Management
Interactive session with FAIR games

Day 3: 26 September 2025 | 13:30 - 17:00 (CET)

The How: In-depth knowledge on a FAIRification process & related services
Take home messages

13:30 - 17:00 (CET)

Day 1: 24 September

The Why: The value and benefits of making data FAIR

WELCOME & INTRODUCTION

13:30	<i>Welcome & Etiquette</i> Suzie-Ann Bakker, World Duchenne Organization
13:35	<i>How to use FAIR for the Benefit of Patients</i> Elizabeth Vroom, World Duchenne Organization
13:45	<i>Introduction to the Program, Desired Key Outcomes and 'LearnFAIR'</i> Claudio Carta and Nawel Lalout

REALISING THE VALUE OF FAIR: BENEFITS, CHALLENGES AND IMPACT

14:05	<i>Value and Benefits of FAIR Explained with a Concrete Example: The Seed banks FAIR Project</i> Mark Wilkinson, FAIR Data Systems
14:35	<i>The role of FAIR Data in Enhancing Research Reproducibility & Data Reuse</i> Ronald Cornet, Amsterdam UMC
15:05	<i>Q&A and discussion with the speakers</i> Moderated

BUILDING TRUST IN FAIR DATA: FROM FUNDING TO CONSENT

15:25	<i>FAIR Data from the Perspective of Funders</i> Ellen Carbo, ZonMW
15:45	<i>Data Protection, Ethics and Regulatory Aspects</i> Annalisa Landi, Benzi Foundation
16:05	<i>GDPR and Data Stewardship: ELSI Information for Researchers and Data Stewards</i> Elize Vlainic, Amsterdam UMC
16:25	<i>Q&A and discussion with the speakers</i> Moderated
16:45	<i>End of Day 1</i>

13:30 - 17:00 (CET)

Day 2: 25 September

The What: FAIR Principles & FAIR Project Management

WELCOME & INTRODUCTION

13:30	Welcome Marco Roos, Leiden University Medical Center
13:32	Recap Day 1 and Introduction to Day 2 Marco Roos, Leiden University Medical Center
13:45	What FAIR means to a patient Simone Lousse, ERN GUARD-Heart
14:05	Ambitions of the HemaFAIR project Petros Kountouris, HemaFAIR
14:25	Q&A and discussion with the speakers Moderated

FROM PRINCIPLES TO PRACTICE: NAVIGATING THE FAIR DATA JOURNEY

14:30	The (Un)FAIR game Marco Roos, Leiden University Medical Center
14:45	The (Un)FAIR game: Lessons Learned Marco Roos, Leiden University Medical Center
15:00	Introduction to the FAIR Principles and Research Data Life Cycle Martijn Kersloot, Amsterdam UMC
15:30	Making Research Data Findable and Accessible in Rare Diseases Bruna Dos Santos Vieira, Radboudumc
16:00	Making Research Data Interoperable and Reusable in Rare Diseases César Bernabé, Leiden University Medical Center
16:30	Building a solid ecosystem for 'Data Visiting' with ERDERA VP Luiz Bonino da Silva Santos, Twente University
17:00	End of Day 2

13:30 - 17:00 (CET)

Day 3: 26 September

The How: Delving into advanced concepts and tools

WELCOME & INTRODUCTION

13:30	Welcome, Recap Day 1 and 2 and Introduction to Day 3 Claudia Carta, Istituto Superiore di Sanità
13:45	What FAIR means to a Privacy Lawyer Geerte van de Loo, Radboudumc
14:05	From Principles to Practice: FAIR Data through the BIND Use Case Sergiu Siminiuc, Duchenne Data Foundation
14:25	Q&A and discussion with the speakers Moderated

IN-DEPTH KNOWLEDGE ON FAIRIFICATION OF DATA

14:30	FAIRification process explained Alberto Camara, Universidad Politécnica de Madrid
14:50	The structure and querying FAIR Data with SPARQL Mark Wilkinson, FAIR Data Systems
15:05	The journey of One Data Element Mark Wilkinson, FAIR Data Systems
15:20	Q&A and discussion with the speakers Moderated

EVOLVING RESEARCH DATA SHARING IN EU CONTEXT

15:30	The European Health Data Space to tackle Rare Diseases Ronald Cornet, Amsterdam UMC
15:50	JARDIN: Alignment of efforts at national level Marco Roos, Leiden University Medical Center
16:10	Lessons learned from the ERN EURO-NMD Registry Hub FAIR project Adrian Tassoni, University Medical Center Freiburg
16:30	Q&A and discussion with the speakers Facilitator: Peter-Bram 't Hoen, Claudio Carta, Nawel Lalout

WRAP-UP

16:40	Closing Remarks Peter-Bram 't Hoen, Radboudumc
16:50	ERDERA FAIR Training Program (Part II & III) - next steps Dimitrios Athanasiou, ERDERA Executive Committee
17:00	End of Training

Contributors

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