

PROGRAM

ONLINE MEETING | 22 NOVEMBER 2022 | 13:00 - 17:00 CET

3rd International Meeting on FAIR Data *Visiting* for Duchenne, Becker & Other Rare Diseases

[Register your participation](#)

13:00 **Welcome** by Elizabeth Vroom 10'
Chair, World Duchenne Organization

GET INSPIRED BY OUR FAIR STORY

13:10 “Finding others in the same boat as me” 5'
Personal message from Lizanne Schreur, young woman with Duchenne

13:15 “How would you describe your FAIR journey?” 15'
Testimonials from five co-authors of The FAIR Guiding Principles for Scientific Data Management and Stewardship
Barend Mons, Mark Wilkinson, Marco Roos, Peter-Bram 't Hoen and Erik Schultes

13:30 How global open FAIR data are changing the world in practice 15'
Erik Schultes, GO FAIR Foundation

13:45 FAIR Data Visisting is now possible for the Duchenne Data Platform 15'
Nawel Lalout, Duchenne Parent Project & Mark Wilkinson, FAIR Data Systems

13:55 Discussion with the speakers (facilitator: *Marco Roos, LUMC*) 15'

A FAIR JOURNEY CAN ONLY BE TAKEN WITH OTHERS

14:10 From the perspective of EURORDIS 10'
Jelena Malinina, EURORDIS

14:20	From the perspective of RaDiOrg, Belgium <i>Montse Urbina, RaDiOrg</i>	10'
14:30	From the perspective of SMA Europe, Germany <i>Nicole Gusset, SMA Europe</i>	10'
14:40	From the perspective of the Rare Diseases GO FAIR Patient Network <i>Michela Onali, Rare Diseases GO FAIR Patient Network</i>	10'
14:50	Duchenne FAIR use-case in an EU funded project: BIND <i>Elvina Sakellariou, Duchenne Data Foundation (DDF)</i>	10'
15:00	Discussion with the speakers (Facilitator: <i>George Paliouras, DDF</i>)	15'
15:15	Break (10 min)	

BUILDING A SOLID ECOSYSTEM FOR DATA VISITING

15:30	European Health Data Space and how to join the dots to tackle Rare Diseases <i>Jerome De Barros, European Commission</i>	15'
15:45	<i>The DARWIN project</i> <i>Daniel Leaver Morales, European Medicines Agency</i>	15'
16:00	EJP-RD Virtual Platform: How will the VP integrate into the CRN of the Rare Disease Partnership? <i>Ana Rath, European Joint Program on Rare Diseases (EJP-RD), INSERM</i>	15'
16:15	ERN's perspective on Clinical Reported Outcomes and Patient Reported Outcomes: values and limitations <i>Leo Schultze Kool, RadboudUMC, ERN VASCERN</i>	15'
16:30	Real example of Semantically Interoperable Care Pathway (video) <i>Martin Ingvar, Karolinska Institutet</i>	15'
16:45	Closing remarks & next steps <i>Peter-Bram 't Hoen, RadboudUMC & Dimitrios Athanasiou, WDO</i>	15'
17:00	End of Meeting	

Hosts & Speakers

About the hosts

Elizabeth Vroom, Chair, World Duchenne Organization

Mirjam Franken, Project Manager, Duchenne Parent Project

Suzie-Ann Bakker, Communications Manager, World Duchenne Organization

Nawel Lalout, FAIR Project Manager, World Duchenne Organization

About the speakers

Lizanne Schreur, Digital Television Director, Author and woman living with Duchenne

Barend Mons, Ambassador of GO FAIR and President of CODATA, The Netherlands

Mark D. Wilkinson, BBVA-UPM Industry Chair on Biotechnology, Co-Founder of FAIR Data Systems, Spain

Marco Roos, Associate Professor, Group leader of the LUMC BioSemantics group, The Netherlands

Peter-Bram 't Hoen, Professor of Bioinformatics, Head Centre for Molecular and Biomolecular Informatics, RadboudUMC, The Netherlands

Erik Schultes, FAIR Implementation Lead, GO FAIR Foundation, The Netherlands

Jelena Malinina, Digital Health Expert, Data Director, EURORDIS

Montse Urbina, Scientist at FAPA Hereditary Colorectal Cancer Project, Belgium

Nicole Gusset, President at SMA Europe, Germany

Michela Onali, Co-chair RDs GO FAIR Patient Network, Cross Cultural Mediator and Rare Disease Advocate, Italy,

Elvina Sakellariou, Project Manager at Duchenne Data Foundation, Greece

George Paliouras, Chairman Duchenne Data Foundation, Science Researcher at NCSR, Greece

Jerome De Barros, EC Policy Officer, Digital Health, The Netherlands

Daniel Leaver Morales, Pharmacovigilance Risk Assessment Committee Member at European Medicines Agency, The Netherlands

Ana Rath, Director INSERM, US14 - Orphanet, France

Leo Schultze Kool, Former Head of the Interventional Radiology department at the RadboudUMC

Martin Ingvar, Professor and former Dean of Research at Karolinska Institutet, Sweden

Dimitrios Athanasiou, PDCO member at EMA, Patient Representative at EURORDIS, Greece