

WEDNESDAY, 12 JUNE 2024

19.30/20.00	Arrival and Speakers Dinner at the Hotel	<i>BY INVITATION ONLY</i>
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THURSDAY, 13 JUNE 2024 8.30 – 17.40 CEST

8.30 – 8.45	Registration	
8.45 – 8.50	Opening Ceremony and Welcome	<i>Claudia Fuchs (EURORDIS) Leonardo Panzeri (AS.ITO.I.)</i>

SESSION 1: Multi-national strategies for Patient Advocacy in OI

Moderators: *Claudia Fuchs & Eve Hewitt*

8.50 – 9.10	Opening Speech by a Patient: What does it mean living with OI?	<i>Gem Turner</i>
9.10 – 9.25	The European Reference Network on rare bone diseases (ERN-Bond)	<i>Luca Sangiorgi (Istituto Ortopedico Rizzoli)</i>
9.25 – 9.45	The European Registries for Rare Bone and Mineral Conditions (EuRR-Bone)	<i>Claudia Finis (DOIG (German Ostogenesis Imperfecta Organisation) and Berlin Institute of Health at Charité)</i>
9.45 – 10.05	Patient Engagement Initiatives in Rare Diseases: an Italian Perspective	<i>Annalisa Scopinaro (UNIAMO – Federazione Italiana Malattie Rare)</i>
Lightening talks: European and National Patient Engagement Activities in OI		
10.05 – 10.15	Stronger Together: OIFE's Patient Engagement Initiatives	<i>Anna Rossi (OIFE)</i>
10.15 – 10.25	Introduction to Patient Engagement Activities in Italy	<i>Simona Paveri (AS.ITO.I.)</i>

10.25 – 10.35	Introduction to Patient Engagement Activities in Norway	<i>Inger-Margrethe Stavdal Paulsen (Norsk Forening for Osteogenesis Imperfecta)</i>
10.35 – 10.45	Introduction to Patient Engagement Activities in Spain	<i>Miguel Rodríguez Molina (Asociación Nacional Huesos de Cristal OI España – AHUCE)</i>
10.45 – 10.55	Brittle Bone Society – Support that matters most	<i>Patricia Osborne (Brittle Bone Society - BBS)</i>
10.55 – 11.05	Q/A session	
11.05 – 11.30	Coffee Break	

SESSION 2: Current Treatment Options in OI – a multistakeholder perspective

Moderators: Anna Rossi & Luca Sangiorgi

11.30 – 11.50	Introduction to different treatment options and approaches for OI	<i>Nick Bishop (The University of Sheffield)</i>
11.50 – 12.10	Introduction to the REMEDI4ALL MOI-A Study	<i>Judith Cohen (University of Hull)</i>
Lightening talks: Current ongoing clinical trials with specific focus on challenges and opportunities of Patient Engagement		
12.10 – 12.20	TOPaZ trial	<i>Stuart Ralson (University of Edinburgh)</i>
12.20 – 12.30	The ORBIT Phase II/III trial, a collaborative design to study setrusumab treatment effect in OI	<i>Luigi Picaro (Mereo BioPharma)</i>
12.30 – 12.40	BOOSTB4 Trial: Boost Brittle Bones Before Birth	<i>Cecilia Götherström (Karolinska Institute)</i>
12.40 – 12.50	Q/A session	
12.50 – 14.00	Lunch Break	

SESSION 3: "Patient-centered clinical trial design"

Moderators: Nick Bishop & Claudia Fuchs

Lightening talks: Patient perception and experience in clinical trials		
14.00 – 14.05	Patient Perspective as a Teenager	<i>Emilija and Dace Liepina</i>
14.05 – 14.10	Patient Experience on the ASTEROID Trial	<i>Marie Holm Laursen</i>

14.10 – 14.15	Patient Engagement activities within the R4ALL demonstrator (MOI-A Study)	<i>Marina O’Callaghan</i>
14.15 – 14.25	Q/A session	
Lightening talks: Presentation of different initiatives in OI		
14.25 – 14.35	The Impact Survey Initiative	<i>Oliver Semler (University of Cologne)</i>
14.35 – 14.45	Adult Health Initiative	<i>Stuart Ralson (University of Edinburgh)</i>
14.45 – 14.55	Care4BrittleBones Initiative Key4OI	<i>Lida Zhytnik (Amsterdam UMC)</i>
14.55 – 15.05	Q/A session	
Lightening talks: Quality of Life assessment (QoL) and patient related innovative outcome measures in clinical trials in OI		
15.05 – 15.15	QoL assessment in OI	<i>Nick Bishop (The University of Sheffield)</i>
15.15 – 15.25	Developing patient related outcome measures in clinical trials for rare bone disorders	<i>TBC</i>
15.25 – 15.35	Developing patient related outcome measures on mobility in rare bone disorders	<i>Luca Sangiorgi (Istituto Ortopedico Rizzoli)</i>
15.35 – 15.50	Regulatory perspective on innovative outcome measures – how can patients contribute?	<i>Violeta Stoyanova-Beninska (Committee for Orphan Medicinal Products)</i>
15.50 – 16.00	Patient perspective on innovative outcome measure – how to advocate?	<i>Inger-Margrethe Stavdal Paulsen (Norsk Forening for Osteogenesis Imperfecta)</i>
16.00 - 16.20	Coffee Break	

PANEL DISCUSSIONS

16.20 – 16.50	Panel discussion on innovative outcome measures in clinical trials	<i>Moderators: Inger-Margrethe Stavdal Paulsen & Eve Hewitt Panelists to be announced</i>
16.50 – 17.20	(Panel discussion) Ask the experts: how to become a patient advocate in OI?	<i>Moderators: Marina O’Callaghan – Claudia Fuchs Panelists to be announced</i>
17.20 – 17.30	Wrap Up of the Panel Discussions	<i>Claudia Fuchs – Eve Hewitt</i>
17.30 – 17.40	Patient engagement in early Health Technology Assessment (HTA)	<i>Zsuzsanna Petyko (Syreon)</i>

GET TOGETHER

19.30/20.00	Speakers Dinner in the Center of Bologna	<i>BY INVITATION ONLY</i>
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**FRIDAY, 14 JUNE 2024
9.00 – 11.00 CEST**

9.00 – 11.00	Presentation of the workshop on early HTA assessment	<i>BY INVITATION ONLY</i>
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