



OIFE Topical Meeting 2023: Balancing Life with OI: Pain and its impact
9-10 June 2023
Stockholm, Sweden

Programme

Thursday 8 June	
From 17:00	<i>Arrival and registration</i>
Friday 9 June	
07:30-09:00	<i>Breakfast and registration</i>
09:00-10:30	Introduction to pain in OI and other rare bone conditions Moderators: Eva Åström (Sweden) / Ute Wallentin (Germany)
09:00	Welcome Eva Åström (Stockholm, Sweden) Lena Lande Wekre (Oslo, Norway) Ingunn Westerheim (OIFE)
09:10	IS01 Keynote lecture: What is pain? Audun Stubhaug (Oslo, Norway)
09:40	IS02 What are the causes and different types of pain in OI? Jacqui Clinch (Bristol, UK)
10:00	IS03 A multicenter study to evaluate pain characteristics in osteogenesis imperfecta: findings from the BBDC Mercedes Rodriguez Celin (Chicago, USA)
10:15	IS04 Chronic pain in adults with OI and its relationship to appraisal, coping, and quality of life: A cross-sectional study Rubén Muñoz Cortés (Valencia, Spain)
10:30-11:00	<i>Coffee break</i>
11:00-13:00	Assessment and measurement of acute and chronic pain Moderators: Jacqui Clinch (UK) / Inger-Margrethe Stavdal Paulsen (Norway)

11:00-11:10	<i>Living with pain and OI – anonymous testimonies</i>
11:10	IS05 How to assess pain: pros and cons of different tools Mercedes Rodriguez Celin (Chicago, USA)
11:30	IS06 Neonatal pain Michael Bober (Wilmington, USA)
11:45	IS07 Assessing pain in children Kelly Thorstad (Montreal, Canada)
12:00	IS08 Assessing pain in adults with OI Richard Keen (London, UK)
12:15-13:00	Oral communications Moderators: Jacqui Clinch (UK) / Inger-Margrethe Stavdal Paulsen (Norway)
12:15	S01 Sleep quality, excessive daytime sleepiness and increased risk for OSA in patients with osteogenesis imperfecta Linda Lušić (Split, Croatia)
12:25	S02 Evaluation of mobility associated symptoms in Argentinian patients with Osteogenesis Imperfecta. Application of the STEMS tool (Screening Tool for Everyday Mobility and Symptoms for Skeletal Dysplasias) Mercedes Rodriguez Celin (Chicago, USA)
12:35	S03 First results of using the Key4OI PROMIS questionnaires for measuring quality of life in children with OI, compared to children with other types of skeletal dysplasia Marjolein Verhoef (Utrecht, Netherlands)
12:45	S04 The European Registry for Rare Bone and Mineral Conditions (EuRR-Bone): collecting patient reported outcomes on osteogenesis imperfecta Ana Priego (Leiden, Netherlands)
12:50	S05 Pain and fractures in osteogenesis imperfecta: results from a survey of patients and caregivers Ali Skrinar (Novato, USA)
12:55	S06 Sleep parameters in adults with OI and their associations with pain and fatigue Marie Coussens (Ghent, Belgium)

13:00-14:15	<i>Lunch and posters (see poster list below)</i>
14:15-15:30	More than just bone pain Moderators: Richard Keen (UK) / Lida Zhytnik (Estonia)
14:15-14:25	<i>Living with pain and OI – anonymous testimonies</i>
14:25-14:40	IS09 Neuromuscular health and function in children with osteogenesis imperfecta Alex Ireland (Manchester, UK)
14:40-14:55	IS10 Pain and its correlates with physical and psychological functioning in adults with OI Marie Coussens (Ghent, Belgium)
14:55-15:05	IS11 Pain and basilar invagination Eva Åström (Stockholm, Sweden)
15:05–15:15	IS12 Osteogenesis imperfecta and gastrointestinal pain – what do we (not) know? Lena Lande Wekre (Oslo, Norway)
15:15-15:30	Oral communications Moderators: Richard Keen (UK) / Lida Zhytnik (Estonia)
15:15	S07 Perceived dental care needs and concerns of individuals with osteogenesis imperfecta Coreen Kelday (Dundee, UK)
15:20	S08 Biological plates in the surgical treatment of imperfect osteogenesis Ana Maria Bueno Sanchez (Madrid, Spain)
15:25	S09 Intramedullary canal sclerosis - a possible complication of prolonged bisphosphonate therapy in children with osteogenesis imperfecta Željko Jeleč (Zagreb, Croatia)
15:30-16:00	<i>Coffee break</i>
16:00-16:30	Debate: Can pain play a role as an endpoint and in evaluating new therapies? Moderator: Michael Bober (USA) Cathy Raggio (New York, USA) Ali Skrinar (Vice President Endpoint Development and Strategy, Ultragenyx)

	<p>Inger-Margrethe Stavdal Paulsen (patient representative)</p> <p>Other speakers tbc</p>
16:30-17:30	<p>How does pain in OI compare with other bone conditions?</p> <p>Moderators: Marelise Eekhoff (Netherlands) / Oliver Gardner (UK)</p>
16:30	<p>IS13</p> <p>Pain and OI – similarities and differences between other bone conditions</p> <p>Alison Boyce (Bethesda, USA)</p>
16:50	<p><i>Anonymous testimonies (from various RBDs)</i></p>
17:05	<p>Discussion between patient reps to talk about commonalities and differences and how we can work together on pain</p> <p>Marie Fahlberg (FOPSverige) Tenna Toft (XLH Alliance) Rebecca Tvedt Skarberg (OIFE) Meryl Chambers (Soft Bones HPP UK Foundation) Liana la Forgia (Italian Patient Association on Multiple Osteochondromas)</p>
17:30-18:00	<p>Oral communications</p> <p>Moderators: Marelise Eekhoff (Netherlands) / Oliver Gardner (UK)</p>
17:30	<p>S10</p> <p>Pain and Quality of Life in patients with Fibrous Dysplasia/McCune Albright Syndrome: a prospective follow up study</p> <p>Oana Bulaicon (Leiden, Netherlands)</p>
17:40	<p>S11</p> <p>Working life with rare diagnosis</p> <p>Brede Dammann (Oslo, Norway)</p>
17:50	<p>S12</p> <p>Pain rehabilitation of patients with a rare skeletal dysplasia – adapting to their special needs within existing rehabilitation programs</p> <p>Ariane Kwiet (Oslo, Norway)</p>
17:55	<p>S13</p> <p>Use of medical care by individuals with osteogenesis imperfecta in the Netherlands for neurological and pain-related issues</p> <p>Silvia Storoni (Amsterdam, Netherlands)</p>
18:00	<p><i>End</i></p>
19:00-20:00	<p><i>Welcome reception (for all)</i></p>
20:00-22:00	<p><i>Conference dinner (tickets required)</i></p>

Saturday 10 June	
08:00-08:45	Update on Clinical Trials in OI Programme tbc
09:00-11:00	The IMPACT of pain in OI Moderators: Cathy Raggio (USA) / André Wittwer (Norway)
09:00-09:10	<i>Living with pain and OI – anonymous testimonies</i>
09:10	IS14 IMPACT Survey: background and overview Samantha Prince (Abingdon, UK)
09:25	IS15 Self-reported prevalence and impact of pain in persons with osteogenesis imperfecta (OI): some perspectives from the IMPACT study Lena Lande Wekre (Oslo, Norway)
09:40	IS16 Understanding the connection between pain in OI and mental health, and the impact on sleep and fatigue Andrew Wiese (Houston, USA)
10:00	Balancing ambitions with pain in OI Karen Braitmayer (USA) / Jacob Wittorff (Denmark)
10:15	IS17 Parenting a child in pain Kis Holm Laursen (Denmark)
10:30	IS18 Pain's impact on relationships and sexuality AnnBett Kirkebæk (Aarhus, Denmark)
10:45	IS19 The Pain and OI Survey Michael Stewart (OIF, USA)
11:00-11:20	<i>Coffee break</i>
11:20-11:50	Basic science and pain Moderators: Antonella Forlino (Italy) / Taco van Welzenis (Netherlands)
11:20	IS20

	Pain mechanisms in heritable collagen disorders: lessons learned from the Ehlers-Danlos Syndromes Fransiska Malfait (Ghent, Belgium)
11:50-12:50	Managing pain in OI (part 1) Moderators: Kis Holm Laursen (Denmark) / Lena Lande Wekre (Norway)
11:50	IS21 How we work in the MDT pain clinic: Bristol and Oslo Jacqui Clinch (Bristol, UK) / Audun Stubhaug (Oslo, Norway)
12:10	IS22 Modalities to deal with pain caused by fractures and surgeries Cathy Raggio (New York, USA)
12:30	IS23 Pharmacological pain management Richard Keen (London, UK)
12:50-14:00	<i>Lunch and posters (see poster list below)</i>
14:00-15:45	Managing pain in OI (part 2) Moderators: Mercedes Rodriguez Celin (USA) / Rebecca Tvedt Skarberg (Norway)
14:00	IS24 Therapeutic pain management principles in OI Sophie Barlow (London, UK)
14:20	IS25 Physical activity in OI: A good natural medicine for pain and health in OI Miguel Rodríguez Molina (Madrid, Spain)
14:35	IS26 Educating various target groups Kelly Thorstad (Montreal, Canada)
14:50	IS27 A toolbox for pain in OI: empowering patients to take charge of their health Ariane Kwiet (Oslo, Norway)
15:05-15:45	Oral communications Moderators: Mercedes Rodriguez Celin (USA) / Rebecca Tvedt Skarberg (Norway)
15:05	S14 Transition and Follow-up in Adult OI Jannie Hald (Aarhus, Denmark)
15:15	S15

	Pain and its biopsychosocial impact in children with skeletal dysplasias Saunya Dover (Ottawa, Canada)	
15:25	S16 Effect of blood flow restriction training on bone, muscle, pain, and fatigue in adults with osteogenesis imperfecta type I: a protocol proposal of a randomized controlled clinical trial Marie Coussens (Ghent, Belgium)	
15:35	S17 Impact of advanced therapy on pain in OI Clara Rodríguez (Bilbao, Spain)	
15:45-16:00	Closing remarks and pink elephants! Ingunn Westerheim (OIFE, Norway) Moderator: Lena Lande Wekre (Norway)	
16:00-16:30	<i>Coffee break and departure for those not attending OIFE and SFOI meetings</i>	
FOR MEMBERS OF OIFE, SFOI & INVITED GUESTS ONLY <i>(separate registration required)</i>		
16:30-19:00	OIFE Annual General Meeting	Swedish Association for Osteogenesis Imperfecta (SFOI)
20:00-22:00	<i>2 course AGM dinner (included)</i> <i>OIFE & SFOI</i>	
Sunday 11 June FOR MEMBERS OF OIFE, SFOI & INVITED GUESTS ONLY		
10:00-13:00	Workshops (OIFE AGM continues if needed)	
13:00	<i>Grab and go lunch</i>	

Posters

(oral communications may also be displayed as additional posters)

S18

Learning Through Film: Contributing to a Balanced Life with OI
Camilla LaHart (Oslo, Norway)

S19

Chronic pain and fatigue in patients with multiple osteochondromas and Ollier disease: A systematic review
Ariane Kwiet (Oslo, Norway)

S20

Balancing function with pain in a child with Type V OI

Frances Baratta Ziska (New York, USA)

S21

The importance of nail follow-up: About a case

Ana Maria Bueno Sanchez (Madrid, Spain)

S22

Disease severity greatly influences quality of life in Indonesian children with osteogenesis imperfecta

Kwari Januar Satriono (Jakarta, Indonesia)