



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

Outline 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
09:00	Welcome Eva Åström (Stockholm, Sweden) Lena Lande Wekre (Oslo, Norway) Ingunn Westerheim (OIFE)
09:10	Keynote lecture: What is pain? Audun Stubhaug (Oslo, Norway)
09:40	What are the causes and different types of pain in OI? Jacqui Clinch (Bristol, UK)
10:00	Findings from the BBDC Multicenter Study on Pain Characteristics in OI Mercedes Rodriguez Celin (Chicago, USA)
10:15	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
11:00-11:10	<i>Living with pain and OI – anonymous testimonies</i>
11:10	How to assess pain: pros and cons of different tools Mercedes Rodriguez Celin (Chicago, USA)
11:30	Neonatal pain Michael Bober (Wilmington, USA)

11:45	Assessing pain in children Kelly Thorstad (Montreal, Canada)
12:00	Assessing pain in adults with OI Richard Keen (London, UK)
12:15-13:00	Oral communications
13:00-14:15	<i>Lunch and posters</i>
14:15-15:30	More than just bone pain
14:15-14:25	<i>Living with pain and OI – anonymous testimonies</i>
14:25-14:40	Neuromuscular health and function in children with osteogenesis imperfecta Alex Ireland (Manchester, UK)
14:40-14:55	Pain and its correlates with physical and psychological functioning in adults with OI Marie Coussens (Ghent, Belgium)
14:55-15:05	Pain and basilar invagination Eva Åström (Stockholm, Sweden)
15:05–15.15	Gastrointestinal pain Lena Lande Wekre (Oslo, Norway)
15:15-15:30	Oral communications
15:30-16:00	<i>Coffee break</i>
16:00-16:30	Debate: Is pain a potential end point in clinical trials? Panel tbc
16:30-17:30	Workshop: how does pain in OI compare with other bone conditions?
16:30	Pain and OI – similarities and differences between other bone conditions Alison Boyce (Bethesda, USA)
16:50	<i>Anonymous testimonies (from various RBDs)</i>
17:05	Discussion between patient reps to talk about commonalities and differences and how we can work together on pain Meryl Chambers (Soft Bones HPP UK Foundation) Marie Fahlberg (FOPSverige) Liana la Forgia (Italian Patient Association on Multiple Osteochondromas) Tenna Toft (XLH Alliance) Rebecca Tvedt Skarberg (OIFE)
17:30-18:00	Oral communications

19:00-20:00	<i>Welcome reception</i>
20:00-22:00	<i>Conference dinner (separate fee)</i>
Saturday 10 June	
09:00-10:45	The IMPACT of pain in OI
09:00-9:10	<i>Living with pain and OI – anonymous testimonies</i>
09:10	Findings from the IMPACT survey Lena Lande Wekre (Oslo, Norway)
09:25	The Pain and OI Survey Michael Stewart (OIF, USA)
09:40	Understanding the connection between pain in OI and mental health, and the impact on sleep and fatigue Andrew Wiese (Houston, USA)
10:00	Work/life balance Karen Braitmayer (USA) / Jacob Wittorff (Denmark)
10:15	Parenting a child in pain Kis Holm Laursen (Denmark)
10:30	Pain's impact on relationships and sexuality AnnBett Kirkebæk (Aarhus, Denmark)
10:45-11:15	<i>Coffee break</i>
11:15-12:00	Basic science and pain
11:15	Pain mechanisms in heritable collagen disorders: lessons learned from the Ehlers-Danlos Syndromes Fransiska Malfait (Ghent, Belgium)
11:40	Oral communications
12:00-13:00	Managing pain in OI (part 1)
12:00	How we work in the MDT pain clinic: Bristol and Oslo Jacqui Clinch (Bristol, UK) / Audun Stubhaug (Oslo, Norway)
12:20	Modalities to deal with pain caused by fractures and surgeries Cathy Raggio (New York, USA)
12:40	Pharmacological pain management Richard Keen (London, UK)

13:00-14:15	<i>Lunch and posters</i>	
14:15-15:50	Managing pain in OI (part 2)	
14:15	Therapeutic pain management principles in OI Sophie Barlow (London, UK)	
14:35	Physical activity and pain Miguel Rodríguez Molina (Madrid, Spain)	
14:50	Educating various target groups Kelly Thorstad (Montreal, Canada)	
15:05	A toolbox for pain in OI: empowering patients to take charge of their health Ariane Kwiet (Oslo, Norway)	
15:20	Oral communications	
15:50-16:00	Closing remarks and pink elephants! Ingunn Westerheim (OIFE, Norway) Moderator: Lena Lande Wekre (Oslo, 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>	