

DRAFT PROGRAMME “BALANCING LIFE WITH OI” AND OIFE/SFOI MEETINGS

The programme for the topical meeting “Balancing Life with OI” will consist of a combination of longer talks from invited speakers, shorter oral presentations based on abstract selection, poster presentations, workshops and panel discussions including both people with OI and professionals.

Thursday June 8th	
17:00...	<i>Arrival and registration</i>
Friday June 9th	
07:30-09:00	<i>Breakfast and registration</i>
09:00-10:45	Pain - introduction to pain in OI and other rare bone conditions What is pain? Pain in rare bone conditions – similarities and differences What are the causes of pain in OI? Findings from the multicenter study in the US Chronic pain in adults with OI – appraisal, coping and quality of life
10:45-11:15	<i>Coffee break</i>
11:15-11:30	<i>Living with pain and OI – anonymous testimonies</i>
11:30-13:00	Assessment and measurement of acute and chronic pain Assessment of pain – pros and cons of various pain assessment tools How to differentiate between different types of pain in OI? Assessing pain in different age groups Intensity, impact or interference?
13:00-14:15	<i>Lunch</i>
14:15-15:15	Oral communications (based on abstracts)
15:30-16:00	<i>Coffee break</i>
16:00-16:30	Panel debate Can pain be a potential end point?
16:30-17:15	Does pain have a place in basic research? Pain in mice with OI Pain pathways – how do they work? Can new and emerging therapies have an effect on pain pathways?
17:15-17.40	Mind the gap – findings from the OIF and OIF pain survey Discussion – what are the existing knowledge gaps?
17:40-17.50	<i>Living with pain and OI – anonymous testimonies</i>
17:50-18.00	Summary and practical information
19:00-20:00	<i>Welcome reception</i>
20:00-22:00	<i>Conference dinner (separate fee)</i>
Saturday June 10th	
09:00-10:45	The IMPACT of pain in OI Findings from the IMPACT survey How does pain impact quality of life? Understanding the connection between pain in OI and mental health Sleep quality and fatigue Pain and its impact on mobility Pain’s impact on relationships and family Pain and work/life balance

10:45-11:00	Coffee break
11.00-11.15	<i>Living with pain and OI – anonymous testimonies</i>
11:15-11.45	More than just bone pain Soft tissue, inflammation, hypermobility and pain Basilar invagination and pain Gastrointestinal causes of pain
11:45-12:45	Managing pain in OI Modalities to deal with pain caused by fractures and surgeries Multidisciplinary approaches in the pain clinic Pharmacological pain management Other types of pain management Pain and exercise
12:45 -13:15	Living with pain – similarities and differences between rare bone conditions For instance (more conditions might be included): OI, XLH, HPP, FOP, TIO, MO/MHE
13:15-14:30	<i>Lunch</i>
14:30-15.15	A toolbox for pain and OI Presentation of toolbox from the OI and Pain project Empowering people with rare bone conditions to take charge of their health
15:15-15.45	Educational resources What already exists? Debate: What kind of educational resources do we need?
15:45-16.00	Summary and closure
16:00-16:30	<i>Coffee break</i>
FOR MEMBERS OF OIFE, SFOI AND INVITED GUESTS ONLY	
16:30-19:00	OIFE Annual General Meeting – separate registration SFOI meeting – separate registration XLH Alliance Membership meeting (TBC) – separate registration
20:00-22:00	<i>2 course OIFE & SFOI dinner (included)</i>
Sunday June 11th	
FOR MEMBERS OF OIFE, SFOI AND INVITED GUESTS ONLY	
10:00-13:00	Workshops (OIFE AGM continues if needed) SFOI workshops - TBC Other workshops – TBC
13:00	<i>Grab and go lunch</i>

Draft version: December 16th 2022