

Quality of Life in Rare Liver Disorders

02.07-03.07.2021

Copenhagen Consensus Meeting (workshop?)

Day 1	
12:30 - 13:30	Registration and lunch
13:30-14:00	Welcome, Overview and Aims of the Workshop
14:00 - 14:25	Genetic cholestatic liver diseases
14:30 - 15:30	Session 1 <ul style="list-style-type: none">- Short introduction video with a young patient- QoL in paediatric Autoimmune liverdisease- QoL in teenagers and young adults and the role of the parents - does it progress into adulthood?
15:45 – 17:00	Session 2 (20 min each + 5 min questions) <ul style="list-style-type: none">- Fibro-Polycystic liver disease- How to improve QoL for rare disease patients: prevention and treatment- Genetic counselling and family planning
17:00 - 17:15	break
17:15 - 17:30	Summary of session 1 and 2 – Discussion: Issues to prioritize?
17:30 - 18:00	Groups of 3-4: In what way do we as clinicians accommodate QoL?
18:30	Meet for dinner
Day 2	
09.00 – 10.00	Voice from patient organisations: How do we welcome teenagers and parents in adult care
10.00 – 10.15	Coffee break
10.15 – 11.45	Session 4: <ol style="list-style-type: none">1. PBC2. PSC3. AIH
11.45-12.00	Fruit break
12.00-13.30	Round-off session: What will be the new initiatives after the CPH consensus QoL meeting? Position paper special adolescent issues, transition? Family planning?
13.30-14.00	Lunch bag and goodbye