

# PROGRAM

## DAY 1



9.00	<b>Welcome</b>	Stefanie Märzheuser (GER), Judith Lindert (GER)	<b>Chairs</b>
9.05 - 10.30	<b>I Providing the theoretical framework of parents support groups in pediatric rare diseases: <i>Hirschsprungs Disease &amp; total colonic aganglionosis</i></b> Sabine Alexander (GER), Marijke Pfaff-Jongmann (NL), Karolina Staszkiwicz (PL), Carlotta de Filippo (I) <b>II Common needs in uncommon conditions: core components that reflect the need of parents and patients in</b> A) <i>Hirschsprung Disease and B) total colonic aganglionosis</i> Ernica Pathway and Patient Journey-Involvement of Patient Association - Sabine Alexander (GER) Ernica Pathway and Patient Journey Carlotta de Filippo (I) <b>Centralisation</b> Pernilla Sternström (S) <b>Discussion</b>		Stefanie Märzheuser, Annette Lemli
10.30 - 11.00	<b>Break</b>		
11.00 - 13.00	<b>Core Outcomes Patient and Physician View</b> <b>III From doctor side: Core Outcome Care Team perspective</b> a) <b>Long-term Monitoring and Clinical Evaluation</b> -CSOR: <i>Children's Surgery Outcome Reporting program - Core Outcome Hirschsprung</i> Ben Allin (UK) - <i>Longitudinal Outcome Total Colonic</i> Alessio Prini Prato (I) b) <b>Long-term Quality of Life, Sexual Function</b> - <i>Sexual Function</i> Joseph Davidson (UK) - <i>Quality of Life Evaluation Hirschsprungs</i> Anders Holle (N) c) <b>Longitudinal individual follow up</b> - <i>Smart Text to ameliorate clinician reported Data</i> Shehryer Naqvi (UK) <b>IV Patient centered view</b> <b>From patient side: Core Outcome Patient perspective - Panel Discussion</b> Annette Lemli (GER), Sabine Alexander (GER), Duccio Cavalieri (I), Karolina Staskiewicz (PL), Marijke Pfaff-Jongmann (GER) <b>Discussion</b> <b>Postoperative motility problems</b> Udo Rolle (GER), virtual		Roxana Rasoulli-Kirchmeier, Judith Lindert
13.00- 14.30	<b>Lunch Break</b>		
14.30 - 15:30	<b>V Perioperative Care and Bowel Management</b> - <i>Physicial Associate Role within GOSH colorectal Team</i> Nikita Halai (UK) - <i>Perioperative bowel management</i> Judith Lindert (GER) - <i>Bowel Management Homecare</i> Galina Garbolinski (GER) - <i>Bowel Management Training Seminar</i> Sabine Alexander (GER)		Sabine Alexander, Carlotta de Filippo
15.30 - 16.00	<b>Break</b>		
16.00 - 17.30	<b>VI Surgical Strategies Hirschsprung</b> - <i>Surgical Strategy standard Hirschsprung</i> Joe Curry (UK) - <i>Surgical Strategy standard Hirschsprung</i> Jan-Hendrik Gosemann (GER) - <i>Surgical Strategy standard Hirschsprung</i> Andrzej Golebiewski (PL) - <i>Ernica guideline rectosigmoid for the management of rectosigmoid Hirschsprung's disease</i> Célia Crétolle (P), virtual <b>Discussion</b>		Stefanie Märzheuser Annita Budzanowski
18:30	<b>Drinks by the Beach</b>		

# DAY 2



9.15 - 10.15	<b>VII Mixed and beyond Hirschsprungs</b> <i>Histopathology: Pearls, Pitfalls and perspectives</i>  <i>Diagnostic Pathway on Hirschsprung's disease in paediatric patients</i>  <i>Contributions of a Specialist Nurse Team TIC-PEA- Example of peer mentoring</i>  <b>Discussion</b>	Andreas Ebersdobler (GER)  Annita Budzanowski (UK) Julie Ann-Milburry (UK) Christina Stefanescu-virtual (GER)	Paola Midrio, Anna Modrzyk
10.15 - 10.45	<b>Break</b>		
10.45 - 12.00	<b>VIII Surgical Strategies Total Colonic aganglionosis</b> <i>Preoperative management TCA</i> <i>Surgical Approach</i> <i>Surgical Approach</i> <b>Discussion</b>	Paola Midrio (I) Stefanie Märzheuser (GER) Alessio Prini Prato (I)	Joe Curry Judith Lindert
12.00 - 13.00	<b>IX Expert Round</b> <i>My unsolved questions and cases</i>  <b>Case I</b> Anna Modrzyk (PL) <b>Case III</b> Andrzej Golebiewski (PL)  <b>Case II</b> Paola Midrio (I) <b>Case IV</b> Joe Curry (UK)		Stefanie Märzheuser Alessio Prini Prato
13.00 - 14.00	<b>Lunch Break</b>		
14.15 - 16.00	<b>X Transition</b> <b>a) Patient experience and expectations</b> <i>Annette Lemli (GER), Carlotta de Filippo (I), Karolina Staskiewicz (PL)</i> <i>My experience</i> Giovanni Cavalieri (I)  <b>b) Paediatric surgery</b> <b>Speed dating: european transition reality in Hirschsprungs</b>  <i>The dutch experience:</i> <i>The german experience:</i> <i>The italian experience:</i> <i>The polish experience:</i> <i>The austrian experience:</i> <i>The norwegian experience:</i> <i>The swedish experience:</i>  <b>Talk Transition</b>  <b>c) Adult</b> <b>Transition of adolescence with Hirschsprung-adult perspective</b> Erhart von Ammon CI  <b>Discussion</b>	Roxana Rasoulli-Kirchmeier (NL) Felix Schulze (GER) Duccio Cavalieri (I) Michael Parsierbek (PL) Eva Amerstorfer (A) Anders Holle (N) Pernilla Stenström (S)  Joe Curry (UK)	Joe Curry Carlotta de Filippo
16.00 - 16.30	<b>Break</b>		
16:30-18:00	<b>XII Holistic Continence Score- Satellite Seminar</b> - sponsored by European Reference Network – Hybrid  <i>Systematic Review Bowel Function Score</i> <i>Overview over Bowel Function Scores</i> <i>Real-Time Data Collection and Assessment of Standardised Data Outcome Data in Children with Colorectal Conditions</i> <i>Is it possible to get surgeons to agree?</i> <i>View of Patients - Patient Associations</i>  <b>Discussion</b>	Anders Holle (NL) Eva Amerstorfer (GER) Stavros Loukogeorgakis (UK), Judith Lindert (GER) Joe Curry (UK)	Judith Lindert, Eberhard Schmiedeke
18:45-22h	<b>Boat Trip</b>		

# DAY 3

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9.15 - 10.30	<b>XIII Nutrition, Dietician, Microbiom</b> <i>Nutrition aspects for children with Hirschsprung</i> <i>Nutrition Experience in Hirschsprungs</i> <i>Role of Microbiome</i> <i>Gastroenterological Aspects of Hirschsprung</i> <b>Discussion</b>	Lovisa Telborn (S) Hannah Day (UK), Joseph Davidson (UK) Duccio Cavalieri (I) Martina Kohl (GER)	Duccio Cavalieri Martina Kohl
0.30 - 11.00	<b>Break</b>		
11.00 - 13.00	<b>XIV Network Working Strategy/ Position Paper Construct</b> <b>Breakout Groups</b> <b>Nutrition Working Group</b> <b>Childrens Edition</b> <b>Further Collaboration</b>		Joseph Davidson, Judith Lindert
13.00 - 14.00	<b>Summing up and farewell</b>		