

## Early Management of Rare Conditions in the Neonate

Monday 17<sup>th</sup> August 2020

### EVENT PROGRAMME – ZOOM WEBINAR

08.45	Logging in	
09.00	<b>Office for Rare Conditions, Glasgow</b>	Dr Martina Rodie Consultant Neonatologist, RHC Glasgow Liz Dougan, Office for Rare Conditions
09.20	<b>Vein of Galen Malformations</b>	Mr Jo Bhattacharya Consultant Neurointerventionist, KFSHRC, Saudi Arabia. Dr Anne Marie Heuchan Consultant Neonatologist, RHC Glasgow
10.20	<b>A Parent's Experience</b>	Mrs Sameena Javed, Mother
10.30	Coffee Break	
11.00	<b>Babies and Children's Palliative Care Update</b>	Caroline Porter, Diana Children's Nurse, Supportive and Palliative Care Team Royal Hospital for Children Glasgow.
11.40	<b>Newborn screening for inherited haemoglobin disorders - sickle cell disease and thalassemia</b>	Dr Susan Baird Consultant Paediatric Haematologist, NHS Lothian Lead Clinician SPAH Network
12.20	<b>Children with Multiple Congenital Contractures</b>	Mr Rod Duncan Consultant Orthopaedic Surgeon, RHC Glasgow
13.00	Lunch	
13.30	<b>Rare Neonatal Gastrointestinal Conditions</b>	Dr Judith Simpson, Consultant Neonatologist SCANS Network Mr Gregor Walker, Consultant Paediatric Surgeon SCANS Network
14.30	<b>Long term Total Parenteral Nutrition</b>	Dr Andy Barclay Consultant Paediatric Gastroenterologist, Glasgow
15.10	<b>The Patient Journey</b>	Matt Bolz-Johnson, ERN & Healthcare Advisor EURORDIS
16.00	Live Question & Answer session	
16.30	Feedback & Close	