

# CONGENITAL HYPERINSULINISM

## C O N F E R E N C E

Thursday 19 June 2025

08:30 - 08:50	Registration for those attending in-person	
08:50 - 09:00	Welcome and introduction	<b>GOSH Hyperinsulinism Clinical Nurse Specialists</b>
09:00 - 09:20	The history of congenital hyperinsulinism	<b>Professor Khalid Hussain</b> , Professor of Pediatrics, Weill Cornell Medicine-Qatar
09:20 - 09:40	Neonatal hypoglycaemia	<b>Dr Simon Hannam</b> , Consultant Neonatologist, GOSH
09:40 - 10:00	Alternative cerebral fuels in the first five days in healthy term infants: The Glucose in Well Babies (GLOW) study	<b>Professor Deborah Harris PhD FCNZ</b> , Joint Professor, Nursing and Midwifery Research, University of Newcastle, New South Wales Australia
10:00 - 10:15	NHS England – What is a highly specialised service?	<b>Bernie Stocks</b> , Highly Specialised Senior Commissioning Manager, NHS England
10:15 - 10:20	Questions	
10:20 - 10:40	Break	
10:40 - 11:30	Diagnosis, investigation, current and future treatments of hyperinsulinism	<b>Dr Antonia Dastamani</b> , Consultant of Paediatric Endocrinology and Diabetes & Lead of Congenital Hyperinsulinism NHS Highly Specialised Service, GOSH and <b>Dr Sinead McGlacken-Byrne</b> Consultant Endocrinologist, GOSH, <b>Lily Tye</b> , Ward Sister, GOSH, <b>Clare Gilbert/ Kate Morgan</b> , HI CNS, GOSH
11:30 - 11:50	Genetics of CHI	<b>Professor Sarah Flanagan</b> , Professor in Genomic Medicine, University of Exeter, <b>Dr Jayne Houghton</b> , Principal Clinical Scientist, Royal Devon University Healthcare NHS Trust
11:50 - 12:00	PET scans	<b>Susan Becker</b> , Clinical Research Nurse Coordinator, CHOP (Virtual)
12:00 - 12:15	Dietary management and feeding issues	<b>Annaruby Cunjamalay</b> , Highly Specialist Paediatric Endocrine Dietitian, GOSH
12:15 - 12:25	Questions	
12:25 - 13:15	Lunch	

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13:15 - 13:30	Continuous Glucose Monitoring	<b>Dr Helen Couch</b> , Paediatric Registrar in Diabetes & Endocrinology, Cambridge University Hospitals NHS FT (CUH) and <b>Dr Kathryn Beardsall</b> , Consultant Neonatologist, CUH
13:30 - 13:50	Surgical approach to HI	<b>Professor Paolo De Coppi</b> , Consultant Paediatric Surgeon, GOSH
13:50 - 14:05	Neurodevelopmental surveillance in children with hyperinsulinism	<b>Carey Eldred</b> , Highly Specialised Physiotherapist, GOSH
14:05 - 14:20	Psychosocial impact of hyperinsulinism	<b>Dr Daniela Melamed</b> , Senior Clinical Psychologist (Endocrinology), GOSH
14:20 - 14:25	Questions	
14:25 - 14:40	Break	
14:40- 15:00	Research - clinical trials: Case study	<b>Lucinda Dawson</b> , Senior research nurse, GOSH, <b>Dr Elpiniki Beka</b> , Research Fellow, GOSH
15:00 - 15:30	Case studies: NORCHI, CHOP, COOK	<b>Elaine O'Shea</b> , Nurse Specialist, NORCHI (Virtual) <b>Heather McKnight</b> , Pediatric Nurse Practitioner, CHOP <b>Lisa Truong</b> , Nurse Practitioner, COOK
15:30 - 16:15	Patient /Parents stories	TBC
16:15 - 16:35	The Children's Hyperinsulinism Charity and Congenital Hyperinsulinism International	<b>Ciara Grace</b> , Trustee and <b>Amanda Orr</b> , Trustee, The Children's Hyperinsulinism Charity, <b>Julie Raskin</b> , Chief Executive Officer, Congenital Hyperinsulinism International
16:35 - 16:55	Putting compassion back into compassionate care - what does this mean for families with HI?	<b>Professor Sir Al Aynsley-Green</b> , Professor Emeritus of Child Health, University College London
16:55 - 17:00	Questions and summary of meeting	
17:00	Close	