

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	GOSH Hyperinsulinism Clinical Nurse Specialists
09:00 - 09:20	The history of congenital hyperinsulinism	Professor Khalid Hussain , Professor of Pediatrics, Weill Cornell Medicine-Qatar
09:20 - 09:40	Neonatal hypoglycaemia	Dr Simon Hannam , 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	Professor Deborah Harris PhD FCNZ , 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?	Bernie Stocks , 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	Dr Antonia Dastamani , Consultant of Paediatric Endocrinology and Diabetes & Lead of Congenital Hyperinsulinism NHS Highly Specialised Service, GOSH and Dr Sinead McGlacken-Byrne Consultant Endocrinologist, GOSH, Lily Tye , Ward Sister, GOSH, Clare Gilbert/ Kate Morgan , HI CNS, GOSH
11:30 - 11:50	Genetics of CHI	Professor Sarah Flanagan , Professor in Genomic Medicine, University of Exeter, Dr Jayne Houghton , Principal Clinical Scientist, Royal Devon University Healthcare NHS Trust
11:50 - 12:00	PET scans	Susan Becker , Clinical Research Nurse Coordinator, CHOP (Virtual)
12:00 - 12:20	Surgical approach to HI	Professor Paolo De Coppi , Consultant Paediatric Surgeon, GOSH
12:20 - 12:30	Questions	
12:30 - 13:15	Lunch	

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13:15 - 13:30	Continuous Glucose Monitoring	Dr Helen Couch , Paediatric Registrar, Addenbrookes Hospital and Parent
13:30 - 13:45	Dietary management and feeding issues	Annaruby Cunjamalay , Highly Specialist Paediatric Endocrine Dietitian, GOSH
13:45 - 14:00	Neurodevelopmental surveillance in children with hyperinsulinism	Carey Eldred , Highly Specialised Physiotherapist, GOSH
14:00 - 14:15	Psychosocial impact of hyperinsulinism	Dr Daniela Melamed , Senior Clinical Psychologist (Endocrinology), GOSH
14:15 - 14:20	Questions	
14:20 - 14:40	Break	
14:40 - 5:00	Research - clinical trials: Case study	Lucinda Dawson , Senior research nurse, GOSH, Dr Elpiniki Beka , Research Fellow, GOSH
15:00 - 15:30	Case studies: NORCHI, CHOP, COOK	Elaine O'Shea , Nurse Specialist, NORCHI (Virtual) Heather McKnight , Pediatric Nurse Practitioner, CHOP Lisa Truong , Nurse Practitioner, COOK
15:30 - 16:15	Patient /Parents stories	TBC
16:15 - 16:35	The Children's Hyperinsulinism Charity and Congenital Hyperinsulinism International	Ciara Grace , Trustee and Amanda Orr , Trustee, The Children's Hyperinsulinism Charity, Julie Raskin , Chief Executive Officer, Congenital Hyperinsulinism International
16:35 - 16:55	Putting compassion back into compassionate care - what does this mean for families with HI?	Professor Sir Al Aynsley-Green , Professor Emeritus of Child Health, University College London
16:55 - 17:00	Questions and summary of meeting	
17:00	Close	