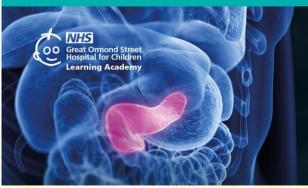


## CONGENITAL HYPERINSULINISM

ONFERENCE

## 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	<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	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 - 12:15	Dietary management and feeding issues	Annaruby Cunjamalay, 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	Dr Helen Couch, Paediatric Registrar, Addenbrookes Hospital and Parent
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	Carey Eldred, 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	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	ТВС
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	