UCL200 / BPSU40: Symposium on Childhood Rare Disease

Tuesday 22 September 2026; 10:00am–5:00pm

Join us for a joint celebration of the collaboration and impact that UCL's Great Ormond Street Institute of Child Health and the British Paediatric Surveillance Unit (BPSU) have had on outcomes for children and families affected by rare diseases in the UK and beyond.

10:00-10:30	**Registration**
Session 1: Welcome and international keynote address	
10:30 10:40	**Welcome** Professor Helen Cross, Director, UCL Great Ormond Street Institute of Child Health **Keynote address** **Population surveillance and rare disease research - the Australian experience** Distinguished Professor Elizabeth Elliott, University of Sydney and Children's Hospital Westmead, Australia / Australian Paediatric Surveillance Unit
11:30-11:45	**Coffee Break**
Session 2: Perspectives on Childhood Rare Disease	
11:45	**Introduction to session** (Chair)
11.50	**RARE Revolution** Joe Rumney & Emma Bishop, RARE Revolution Magazine
12:10	**Collaborating to create a National Paediatric Secure Data Environment** Professor Andrew Taylor, Great Ormond Street Hospital & Rebecca Cosgriff, LifeArc
12:25	**Gene therapy for rare immunodeficiencies** Professor Claire Booth, Zayed Centre for Research into Rare Diseases in Children
12:40	**Role of industry in paediatric rare disease** Professor Alan Boyd MBE, Boyd Consulting
12:55-14:00	**Lunch**
Session 3: Celebrating 40 years of partnership with the British Paediatric Surveillance Unit	
14:00	**Introduction to session** Dr Peter Davis, Chair, British Paediatric Surveillance Unit (BPSU)
14:10	**A new approach to rare disease surveillance: HIV and the BPSU** Professor Claire Thorne, UCL Great Ormond Street Institute of Child Health
14:25	**BPSU impacts on practice and policy: evidence from research** Professor Alastair Sutcliffe, UCL Great Ormond Street Institute of Child Health
14:40	**International responses to emerging diseases: Zika and microcephaly** Dr Rachel Knowles, UCL Great Ormond Street Institute of Child Health
14:55	**Data linkage for long-term outcomes: Childhood Blindness** Professor Jugnoo Rahi, UCL Great Ormond Street Institute of Child Health
14:55-15:30	**Coffee Break**
Session 4: Looking to the future - newborn screening for rare disease	
15:30	**Introduction to session** (Chair)
15:35	**Generation Study: Newborn whole genome sequencing** Dr David Bick, Principal Clinician - Newborn Genomes Programme, Genomics England

15:50	**Evaluating new screening programmes for rare conditions** Professor Anne Mackie, UK National Screening Committee
16:05	**Supporting families affected by rare disease** Nick Meade, Chief Executive, Genetic Alliance
16:20	**Panel Discussion** David Bick, Anne Mackie, Nick Meade, David Elliman, Jugnoo Rahi, Melissa Hill
16:50	**Close**