

# BIMDG Draft Programme – ICC Wales June 2023

## ‘Breaking Boundaries’

### Monday 10<sup>th</sup> June

Evening meeting: sponsored by Sanofi and Immedica

Programme TBC

### Tuesday 11<sup>th</sup> June

09:00-09:30 Registration and coffee

09:30 – 12:00 Parallel sessions

10:30-11:00 Coffee Break

Adult IMD meeting  
Clinical and Scientific trainees meeting  
Clinical Pharmacists meeting  
Dieticians meeting  
Nurses meeting  
Paediatric CSAC meeting  
Paediatric IMD and link clinicians meeting  
Psychologists meeting

12:00 – 13:00 Lunch

<b>13:00 – 14:30</b>	<b>Session 1: The Cutting Edge of IMDs</b>	<b>To invite speaker</b>
13:00-13:30	Clinical experience with newly approved IMD treatments	Prof Simon Jones, Manchester Children’s Hospital
13:30-14:00	Givosiran in the Acute Porphyrias	Dr Danja Schulenburg-Brand, University Hospital of Wales, Cardiff
14:00-14:30	Update on WGS for Newborn Screening	Dr Karina Stone, Genomics England

<b>15:00-16:00</b> (poster walks to start from 15:15)	<b>Poster presentations and Tea and Coffee break</b>	
<b>16:00-17:30</b>	<b>Session 2: Working across borders</b>	
16:00-16:30	Managing IMD patients across challenging geographies	Prof Chris Hendriksz, FYMCA Medical
16:30-17:00	The role of the Advanced Practitioner in IMDs	Anita Inwood, Service Director and Metabolic Nurse Practitioner, Queensland, Australia
<b>17:00-18:00</b>	<b>BIMDG AGM</b>	
<b>19:30</b>	<b>Conference Dinner</b>	

### Wednesday 12<sup>th</sup> June

08:30-09:00	Coffee and registration	
<b>09:00-10:30</b>	<b>Parallel Session 3a: Undiagnosed and Very Rare Disorders</b>	
09:00-09:30	The Syndrome Without a Name (SWAN) clinic	Dr Graham Shortland OBE, C&V UHB
09:30-10:00	Lipidomics and Metabolomics for Rare Disease Diagnosis	Prof Bill Griffiths, Swansea University
10:00-10:30	Challenges in managing very rare disorders	Dr Charlotte Dawson, Queen Elizabeth Hospital, Birmingham
<b>09:00-10:30</b>	<b>Parallel Session 3b – Dietetics</b>	<b>TBC</b>
<b>10:30-11:00</b>	<b>Tea and coffee break</b>	
11:00-11:30	<b>Maggie Lilburn Lecture</b>	Fiona White, Willink Unit, Manchester
11:30-13:00	Members' Papers	
13:00-14:00	Lunch	
<b>14:30-16:00</b>	<b>Session 4: Transitions</b>	
<b>14:00 – 14:30</b>	Educating Healthcare Professionals about Rare Diseases	Dr Lucy McKay, CEO Medics 4 Rare Disease

14:30-16:00	Transitioning from paediatric to adult care – short presentations and Panel discussion (presentations from a medic, nurse, psychologist, dietician, patient representative, and to include a non-IMD service perspective)	<p>Chair: Dr Gisela Wilcox</p> <p>Medic – Chris Hendriksz</p> <p>Psychologist – Dr Stuart Rust, Manchester Foundation Trust</p> <p>Nurse - Liz Morris Lead specialist Nurse for the Lysosomal Disorders Unit at Addenbrooke's</p> <p>Dietician - Clare Dale</p>
<b>16:00</b>	<b>Close</b>	