

**National Museum of
Wales, Cardiff**
Saturday 29 March 2025



Programme

09:30-16:00

All welcome: patients, carers, family and medical professionals	
Time	Oriel Suite
09:30-09:45	REGISTRATION and refreshments
09:45-10:00	Welcome and introductions Dr Vicky McGuire, Sue Burrell and Liz Gill (BPA)
10:00-10:30	Introduction to the porphyrias: Science slam Dr Jasmin Barman-Aksozen
10:30-10:50	EPP patient talk Tiernan (EPP teenager) and Niamh (EPP parent) and Liz Gill
10:50-11:10	AIP patient talk Robyn B (AIP patient) and Sue Burrell
11:10-11:25	Comfort break
11:25-11:45	Iron in EPP Dr Jasmin Barman-Aksozen
11:45-13:00	Q&A panel discussion - cutaneous porphyrias – Liz Gill Panellists: Clinuvel Ltd, Disc Medicine, Portal Therapeutics and Mitsubishi Tanabe Pharma Dr Danja Schulenburg-Brand, Prof Robert Dawe, Dr Jasmin Barman-Aksozen, Niamh and Tiernan, Antony Fearn (EPP patient ambassador)
11:25-13:00	Acute porphyrias to visit museum
13:00-14:00	LUNCH – time to eat and connect with others
14:00-15:15	Q&A panel discussion - acute porphyrias – Sue Burrell Dr Danja Schulenburg-Brand, Mabs Obase, Dr Stephen Lombardelli (AInylam Pharmaceuticals), Robyn B (AIP patient)
14:00-15:15	Skin porphyrias to visit museum
15:15-15:30	Close and final questions
15:30-16:00	CONNECT with refreshments