

**FINAL PROGRAMME: Bipnet Annual Symposium, On Zoom.
14th JUNE 2021**

All times are in BST (UK summer time (British Summer Time))

10:30-11:30 --- Diagnostic lab group session: Chair: Dr Victoria McGuire

11:30-12:30 SESSION 1 (all welcome):

- 11:30 'Chair's Introduction', Dr Robert Sarkany (London, UK)
- 11:45: 'breakout room' discussion session: 'The impact of the Covid pandemic in Porphyria for patients, clinicians and researchers.'
- 12:20: 'Update on forthcoming events and plans from the British Porphyria Association'. Liz Gill, Vice Chair and Administrator, British Porphyria Association
- 12:30: 'The new BIPNET website'. Darren Powell (Liverpool):

12:45-13:15: LUNCH

SESSION 2

13:15-14:15: CLINICAL SESSION (only for porphyria clinical, lab and research Professionals):

- 13:15: Round table clinical case discussion:
- 13:15: Case 1: 'A family with VP and adrenal insufficiency'. Prof Metherell and team, Centre for Endocrinology, William Harvey Research Institute, London, and Prof. El-Sayed and team, Ain Shams university, Cairo.
- 13:30: Case 2: 'A child with homozygous HCP identified on whole genome sequencing'. Denise Darby and Liezel Griffin, Photodermatology and Cutaneous Porphyria Unit, Salford Royal NHS Foundation Trust, Manchester.
- 13:45: Case 3: 'A case of acute porphyria'. Prof Mike Badminton, Cardiff Porphyria Unit.
- 14:00 – Case 4: Case presentation by Dr Vivion Crowley, Head of Department, Biochemistry Dept., St James' Hospital, Dublin.

14:15-14:30 TEA BREAK

14:30-16:00 SESSION 3: NON-CLINICAL SESSION 2 (all welcome):

14:30-15:00 Peter Meissner (Cape Town). 'Variegate porphyria: the South African experience'.

15:00-15:30 Eliane Sardh (Stockholm). 'The therapeutic use of Givosiran'

15:30-16:00 Jean-Charles Deybach (Paris) 'Update on Porphyria emerging therapies'.

16:00 – 16:05: Discussion and closing remarks

**WE ARE GRATEFUL TO
ALNYLAM PHARMACEUTICALS
AND
MITSUBISHI TANABE PHARMA CORPORATION
FOR THEIR SUPPORT WITH EDUCATIONAL AND CONFERENCE GRANTS
WHICH HAVE ENABLED THIS SYMPOSIUM TO OCCUR**

