



British Porphyria Association

136 Devonshire Rd
Durham City
County Durham
DH1 2BL
Charity No: 1089609
www.porphyria.org.uk

Autumn Conference & AGM 2017

Cardiff

Saturday, 7 October 2017: 0930 - 1600

Holiday Inn – Cardiff – North M4, Jct. 32, Merthyr Road, Tongwynlais, Cardiff, CF15 7LH,
Conference rooms: Whitchurch, Radyr and Caerphilly

Key: Red = talks for all attendees; Blue = talks for acute attendees; Purple = talks for EPP/cutaneous attendees

- 0930-1000** **Tea, coffee and registration**
- 1000-1015 Introduction to the porphyrias and the BPA – Liz Gill/Sue Burrell
- 1015-1030 BPA AGM – John Chamberlayne
- 1030-1100 Update from the International Conference on Porphyria – Dr Mike Badminton
- 1100-1125 Complimentary therapies – relaxation techniques – Caroline Pearson
- 1125-1130** **Comfort break** *(and move to breakout room for EPP informal chats 1130-1230)*
- 1130-1200 **Acute talk:** Update on Alynham Pharmaceuticals' research – Dr Mike Badminton
- 1150-1210 **Acute talk:** NAPS specialist nurse role & NAPS survey feedback – Tricia Gardiner
- 1210-1230 **Acute talk:** Drugs in porphyria – Anna Burgess – UKPMIS (UK Porphyria Medicines Information Service)
- 1230-1330** **Lunch** *(followed by acute informal chats in the breakout room from 1330-1430)*
- 1330-1400 **EPP talk:** Update from Clinuvel Pharmaceuticals Ltd – Akash Bhagawati
- 1400-1430 **EPP talk:** Update on EPP & discussion of coping strategies – Dr Mike Badminton
- 1430-1435** **Comfort break** *(and bring the group back together into the main conference room)*
- 1435-1455 Living with AIP – A husband's perspective – Ian Burrell
- 1455-1530 Living with EPP – Antony Fearn and Richard Byford
- 1530-1545 Questions and answer session – with the panel of speakers from the day
- 1545-1615** **Refreshments and informal discussions**

The BPA would like to thank Orphan Europe for providing a grant to assist in the funding of this meeting





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AGM of the British Porphyria Association

On, Saturday 7 October, 2017
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1. Apologies for absence
2. Minutes from last AGM
3. Chairman's Report
4. Treasurer's Report
5. Election of officers
6. Other committee members
7. AOB

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