



British Porphyria Association

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

Information Pack

Autumn Conference and AGM

READING

Saturday, 6 October 2018

**Conference venue: Holiday Inn Reading M4, Jct.10
Wharfedale Road, Winnersh Triangle, Reading, Wokingham,
Berks RG41 5TS**



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Saturday, 6 October 2018: 0930-1630

**Holiday Inn Reading M4, Jct.10
Wharfedale Road, Winnersh Triangle, Reading, Wokingham, Berks RG41 5TS**

Thursday, 20 September 2018

Dear all

Please find within this information pack:

1. A DRAFT programme for the conference
 - a. The timings of the specific sessions/content, including the morning and afternoon slots themselves, as well as the speakers, may still be subject to change, but the main timings of 0930 to 1630 for the day will remain.
 - b. The colour-codes listed below will help you navigate the programme's content:
Key: Red = talks for all; Blue = talks about the acutes; Purple = talks about EPP/cutaneous porphyria
 - c. There should be ample time to speak with other people with the type of porphyria you are most interested in, either during the official breaks or in the specific scheduled times in the breakout room.
 - d. Simple refreshments, as well as a light buffet lunch, will be provided throughout the day, but **if you have any specific dietary needs/allergies that we need to be aware of please let me know ASAP.**

2. Travel and accommodation information for the Holiday Inn Reading M4, Jct.10

There will be signs, on the day, to direct you from the main foyer/reception to the conferencing rooms. **If you have any queries/problems on the day, please call our helpline on 0300 30 200 30.**

In the meantime, if you have any queries about the event, please contact me directly via: sue.burrell@porphyria.org.uk

Looking forward to meeting you all on Saturday 6 October.

Best wishes, Sue Burrell



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Saturday, 6 October 2018: 0930 – 1630

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 – Sue Burrell
- 1015-1030 BPA AGM – Liz Gill, Anne Newton
- 1030-1050 Research trials – what’s really involved for patients – Jonathon Samuel (Research Trial Nurse)
- 1050-1100** *Comfort break (and move to breakout room for EPP informal chats 1100-1200)*
- 1100-1130 **Acute talk:** Update on Alnylam Pharmaceuticals’ research – Dr Stephen Lombardelli
- 1130-1145 **Acute talk:** Symptoms and diagnosis – Professor David Rees (Kings College Hospital, London)
- 1145-1200 **Acute talk:** Treatment and condition management – Professor David Rees
- 1200-1300** *Lunch (after the next talk, acute informal chats will be in the breakout room from 1340-1445)*
- 1300-1340 The impact of living with a chronic health condition – Dr Deepak Ravindran (Royal Berkshire Hospital)
- 1340-1405 **EPP talk:** Update from Clinuvel Pharmaceuticals Ltd – Lachlan Hay and Dr Kathrin Mertens
- 1405-1420 **EPP talk:** Skype interview with Antony an EPP patient/BPA committee member
- 1420-1445 **EPP talk:** Phototherapy – Dr Robert Dawe (Ninewells Hospital, Dundee)
- 1445-1500** *Comfort break (and bring the group back together into the main conference room)*
- 1500-1520 Living with EPP – Light therapy – Richard Byford
- 1520-1540 Living with AIP – A family case study – Liz Gill
- 1540-1610 Questions and answer session with the panel of speakers from the day
- 1610-1630** *Refreshments and informal discussions*



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Travel and accommodation information

Location/venue

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RG41 5TS

0118 944 0444

reservations@hireadinghotel.com

<https://www.hireadinghotel.com/>

Accommodation

The BPA have obtained discounted accommodation rates for anyone wishing to stay at the hotel on Friday 5th October and/or Saturday 6th October, at the following discounted B&B rates:

- Single occupancy room: £75.00
- Double or twin room: £85.00
- Family room: £110.00

In order to obtain these discounted rates, please:

- Call the hotel directly on: +44 (0) 1189 440 444
- Quote:
 - Block code: B30
 - Event Name: British Porphyria Association.
- Please book rooms by 4th September to reserve this favourable rate! The hotel will do their best to honour the rate after this date, but they CANNOT guarantee it!
- Rooms are cancellable, but only up to 14 days before arrival (i.e. they must be cancelled by Friday 21st September), otherwise the full room rate will be charged to the card used to secure your reservation.

Travel information

The hotel's website provides detailed travel information, as follows:

<https://www.hireadinghotel.com/>



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Map



By Car

From M4 London/Heathrow, leave the M4 at Junction 10 and follow the A329(M) towards Reading East. Take the 1st exit signposted Lower Earley/Winnersh/Woodley. At the traffic light take the 1st left into Wharfedale Road. The hotel is located on the left hand side on the corner of Eskdale Road. There is free/secure parking at the hotel for all attendees/guests.

By Train

The hotel is directly next to Winnersh Triangle Rail Station (Reading to Waterloo service), only 1 minute from hotel over landscaped foot bridge, providing easy access to London Paddington in 20 minutes from Reading Central.

By Taxi

We recommend guests arriving by plane contact our local Mini Cab company Top Cars to pre-book a vehicle – 01189 442222.

By Air

The hotel is a 20 minute drive (20 miles) from London Heathrow Airport. Passengers driving from Heathrow to the hotel are recommended to take the M4 (West Bound – heading away from London). Once out of the airport, follow the signs towards the M4 then continue along the M4 until Jct10. Take the A329 (M) exit towards Reading (East). Take the 1st exit towards Winnersh/Woodley/Early/A329. Keep in left lane then take 1st left at Traffic Light into Wharfedale Road. At roundabout take 1st exit at Traffic Light into Eskdale Road. The hotel is on the left.

Passengers taking public transport to the hotel can take the Heathrow Centre Bus to Reading, then the train from Reading to Winnersh Triangle (6 minute journey) on the Waterloo Service (2nd stop from Reading). The hotel is accessed via the white pedestrian bridge directly outside the station.

The hotel is also located only 50 miles from London Gatwick and London Luton Airports.