



**British Porphyria Association**

136 Devonshire Rd  
Durham City  
County Durham  
DH1 2BL  
Charity No: 1089609  
[www.porphyria.org.uk](http://www.porphyria.org.uk)

## **Summer Open Day**

**Saturday, 7 June 2013**

**1000 – 1600**

**Sports and Social Club, Cardiff Medical Centre  
University Hospital of Wales, Cardiff**

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|-----------|---|
| 1000-1030 | Tea, coffee and registration  |
| 1030-1045 | Welcome and introduction from the BPA   |
| 1045-1100 | The National Acute Porphyria Service (NAPS)<br>Ms Tricia Gardiner – Clinical Nurse Specialist               |
| 1100-1115 | Update on future treatments<br>Dr Mike Badminton – Consultant Medical Biochemist                            |
| 1115-1145 | Research studies in acute porphyria<br>Dr Sharon Whatley – Clinical Scientist                               |
| 1145-1200 | Living with porphyria pain – a patient perspective – Sue Burrell  |
| 1200-1230 | Thinking differently about porphyria – the role of psychology<br>Dr Bethan Phillips – Clinical Psychologist |
| 1230-1300 | Complementary therapies<br>Caroline Pearson – Complimentary Therapist                                       |
| 1300-1400 | Lunch   |
| 1400-1420 | Patient story – erythropoietic protoporphyria (EPP) – Claire and Sam Taylor                                 |
| 1420-1450 | Home phototherapy for protoporphyria<br>Prof. Alex Anstey – Consultant Dermatologist                        |
| 1450-1500 | Virtual laboratory tour   |
| 1500-1530 | Question and answer session and close from the BPA<br>Followed by refreshments                              |