



## Dublin Ireland

Sunday 3 March, 2024

## Ashling Hotel, Dublin 10:00-17:00

| All welcome: patients, carers, family and medical professionals |                                                                     |                                      |
|-----------------------------------------------------------------|---------------------------------------------------------------------|--------------------------------------|
| Time                                                            | Room 1: Phoenix Suite                                               |                                      |
| 10:00-10:15                                                     | REGISTRATION and refreshments                                       |                                      |
| 10:15-10:30                                                     | Welcome and introductions                                           | Sue Burrell                          |
| 10:30-11:00                                                     | Introduction to the porphyrias                                      | Liz Gill                             |
| 11:00-11:30                                                     | Patient experience talks on EPP                                     | Patients TBC                         |
| 11:30-11:45                                                     | Comfort break and questions on EPP patient talks                    |                                      |
| 11:45-12:15                                                     | Patient experience talk on AIP                                      | Alicia Cawthorne                     |
| 12:15-13:00                                                     | Interactive session – focusing on young people                      |                                      |
| 13:00-14:00                                                     | LUNCH – time to eat and connect with others                         |                                      |
| Time                                                            | Room 1: Phoenix Suite                                               | Room 2: Montpellier Suite            |
| 14:00-15:30                                                     | ACUTE PORPHYRIAS (AIP, VP & HCP)                                    | SKIN PORPHYRIAS (EPP/XLP, PCT, CEP)  |
|                                                                 | Genetics, treatment options and Q&A                                 | Updates on treatments and Q&A with a |
|                                                                 | with a panel of experts                                             | panel of experts:                    |
|                                                                 | Activities for young people – TBC                                   | Dr Vicky McGuire                     |
| 15:30-17:00                                                     | CLOSE                                                               |                                      |
|                                                                 | Social opportunity and informal quiz connect with others over cake! |                                      |