

Patient Day
Snowdome, Tamworth
Saturday, 3 June 2023 16:00–20:00
Sunday, 4 June 2023 10:00–15:30



Information pack

SnowDome Conference Facility
Tamworth (near Birmingham), Staffordshire
B79 7ND

Within this information pack you will find:

- Social evening programme
- Patient day programme
- Event speakers and panellists
- BPA Trustees and Committee
- Travel information
- Map showing the location of the SnowDome
- Accommodation information
- SnowDome activities/information
- Accessibility information
- Covid safety information

Day 1: Saturday 3 June – Social evening

| All welcome: a chance to CONNECT with others and get involved in activities – refreshments provided | |
|--|------------------------|
| 16:00-16:30 | Welcome and icebreaker |
| 16:30-17:30 | Quiz |
| 17:30-18:00 | Food served |
| 18:00-20:00 | Food and social |

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Day 2: Sunday 4 June – Patient day programme

| All welcome: patients, carers, family and medical professionals | | |
|---|---|--|
| Time | Room 1 – Tirol 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 |
| 11:00-12:00 | Patient experiences <ul style="list-style-type: none">• Victoria's challenge with EPP• Kay's GNR experience and VP• Clare's EPP journey with Scenesse• Salman's living with AIP | <ul style="list-style-type: none">• Victoria Harrold & Antony Fearn• Kay Bryan• Clare Cahalin• Salman Fatmi |
| 12:00-13:00 | LUNCH – time to connect with others | |
| Time | Room 1 – Tirol Suite | Room 2 – Whistler Suite |
| 13:00-15:00 | SKIN PORPHYRIAS (EPP/XLP, PCT, CEP) Updates on treatments and Q&A with a panel of experts: <ul style="list-style-type: none">• Dr Liezel Griffin (Salford)• Dr Robert Dawe (Dundee) TBC• Dr Vicky McGuire (Dundee)• Antony Fearn (EPP patient)• Dr Will Savage – Disc Medicine• Lachlan Hay – Clinuvel | ACUTE PORPHYRIAS (AIP, VP & HCP) Updates on treatments and Q&A with a panel of experts: <ul style="list-style-type: none">• Dr Danja Schulenburg-Brand (Cardiff)• Mabs Obasi (Cardiff)• Liz Gill (acute patient)• Salman Fatmi (AIP patient)• Greg Robertson – Alnylam Pharmaceuticals |
| 15:00-15:30 | CLOSE Final chance to connect with others over cake! | |

We're delighted to have a great panel of people with in-depth knowledge of porphyria joining us on the day, so do please think about any questions you might want to ask them. This is your chance to learn all you can from the experts available. Topics you might like to explore: symptoms, treatments, complications, skin protection, diagnosis, or testing of family members.

If any questions are too specific to one individual or if we do not have time to tackle all questions, we may defer to answering after the event, so that the question can get the attention it deserves.

Feel free to send in any questions in advance to liz.gill@porphyria.org.uk and I can pose them for you.

Charity No 1089609

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Event speakers and panellists

Dr Robert Dawe

Robert is based in the Photobiology Unit at Ninewells Hospital, Dundee. He is a Consultant Dermatologist and Honorary Clinical Reader in the Scottish National Health Service. He runs specialist clinics in phototherapy, porphyria, and other dermatological conditions and is clinical lead for the Scottish Cutaneous Porphyria Service (SCPS). Robert became the new co-chair of the British and Irish Porphyria Network (BIPNET) in 2021.

Dr Liezel Griffin

Dr Liezel Griffin graduated from St George's Hospital Medical School, London in 2010. She completed her dermatology training in Manchester in early 2019 where she joined the Porphyria Clinic at Salford Royal Hospital as a Consultant Dermatologist, working alongside Clinical Biochemistry for porphyria patients in the North West, Liezel is now an active member of the porphyria service in Salford.

Dr Vicky McGuire

Vicky is based in the Photobiology Unit at Ninewells Hospital, Dundee. She is the Principal Scientist for the Scottish Cutaneous Porphyria Service (SCPS) and Honorary Senior Lecturer at the University of Dundee. Current research focuses on mechanisms of drug-induced phototoxicity and biochemical regulation of enzymes involved in haem synthesis. Vicky also became the new co-chair of the British and Irish Porphyria Network (BIPNET) in 2021.

Omabe Obasi (Mabs)

Mabs has been working for over a year as a specialist nurse for the Acute Porphyria Service and Lysosomal Storage Disorders based in the University Hospital of Wales, Cardiff. She works alongside nurses at Kings, London, to support patients not only in Cardiff but across the UK affected by acute porphyria.

Dr Danja Schulenburg-Brand

Based at the University Hospital in Cardiff, Danja has been working as a Consultant in Medical Biochemistry and Metabolic Medicine with the National Acute Porphyria Service (NAPS) over the last few years, alongside Prof Badminton. As part of the All Wales Inherited Metabolic Disease Service, Danja sees both acute and cutaneous porphyria patients.

Patient speakers

Kay Bryan: VP patient

Clare Cahalin: EPP patient

Antony Fearn: EPP patient

Victoria Harrold: EPP patient

Salman Fatmi: AIP patient

Pharmaceutical company panellists

Lachlan Hay

Clinuvel Pharmaceuticals LTD: Director of Global Operations, General Manager European Office

Greg Robertson

Alnylam Pharmaceuticals: Senior Director, Head of International Patient Advocacy and Engagement

Dr Will Savage

Disc Medicine: Chief Medical Officer

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BPA Trustees and Committee

**JOHN CHAMBERLAYNE Chairman**

Around 2004, John became involved with the BPA by helping out with creating a website. Later, some of the established members wanted to pull back from duties and John took the role of Chair. He has the gene for VP, but has not been badly affected. His daughter suffered a severe attack a number of years ago, which led to his initial contact.

**ANNE NEWTON Acting Treasurer**

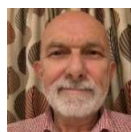
Anne has been involved with the BPA since 2000, after finding the support group while searching for information on the porphyrias, as her daughter was very ill with acute porphyria. Anne was one of the first charity trustees, and has been the BPA Treasurer since 2010, after also fulfilling the role a few years before.

**RICHARD BENNETT Secretary**

Richard became a trustee in 2018 after being involved with the BPA for around four years. He is not a porphyria sufferer, but became aware of the condition when he joined Orphan Europe (now Recordati Rare Diseases), who provide haem arginate. When Richard retired, he started offering support to the BPA.

**KAREN HARRIS Founding Member**

Karen was diagnosed with variegate porphyria in 1982. In 1998, Karen responded to a newspaper article that portrayed porphyria in a poor light. Karen invited people with porphyria to get in touch and a small group decided to try to get the BPA off the ground. Karen was the first Chairman of the association and has been a trustee since the start of the charity.

**ALAN MOLYNEUX Trustee**

Alan has AIP and suffered a very severe attack in his younger years. His daughter has also been affected by severe attacks. Alan has been involved with the charity for many years, doing a stint as Treasurer in 2008-2010. As well as being a trustee, he also assists in the administration of the email helpline.

**LIZ GILL Strategic Lead of Operations and Advocacy**

Affected by AIP since she was 18, Liz has been involved with the BPA for more than 17 years. She's developed an in-depth understanding of porphyria through direct contact with patients and liaising with clinicians nationally and internationally. As the lead for operations and advocacy, Liz is heavily involved with all aspects of the charity, including new drug approval processes in the UK. She is also the patient representative on the Board of the European Porphyria Network (EPNET).

**SUE BURRELL Strategic Lead of Engagement and Advocacy and GPAC President**

Sue has AIP and has been involved with the BPA for over 13 years. Sue is actively involved in the day-to-day running of the charity, its events and working groups, taking a lead in engagement and advocacy activities; she is also instrumental in moving the BPA strategy forwards. In Sept 2019, she became the elected President of the newly formed Global Porphyria Advocacy Coalition (GPAC), an umbrella organisation that aims to support porphyria patient groups across the world.

**ANTONY FEARN EPP Patient Ambassador**

Finally diagnosed with EPP aged 32, Antony linked with the BPA around five years ago during which time he has become increasingly engaged as a patient ambassador, both within the UK and on an international level. He has played a key role in refreshing the BPA website, updating the BPA strategy and event structure, and is keen to investigate the science behind EPP to live with as few limitations as EPP will permit.

**NATASSJA CHADWICK Fundraising and Awareness Working Group**

Natassja's two children, Madison and Isaac, both have EPP. Since their diagnosis Natassja has been passionate about raising awareness on the Isle of Man where the family live and also fundraising for the BPA. More recently, Natassja volunteered to help on the BPA's new working group and recently became a member of the committee.

**VICTORIA HARROLD Fundraising and Awareness Working Group**

Victoria was diagnosed with EPP when she was 24, and recently volunteered to help on the BPA's new working group. She also runs a well-established and successful EPP support group on Facebook. When not helping the BPA, Victoria works in Customer Services and has three guinea pigs that keep her busy and entertained when stuck indoors.

**KIRSTINE CHAMBERLAYNE Committee Member**

Kirstine has been involved with the BPA for over 16 years. Taking on the role of Minutes Secretary for many years, she is now involved with proofreading and checking documents.

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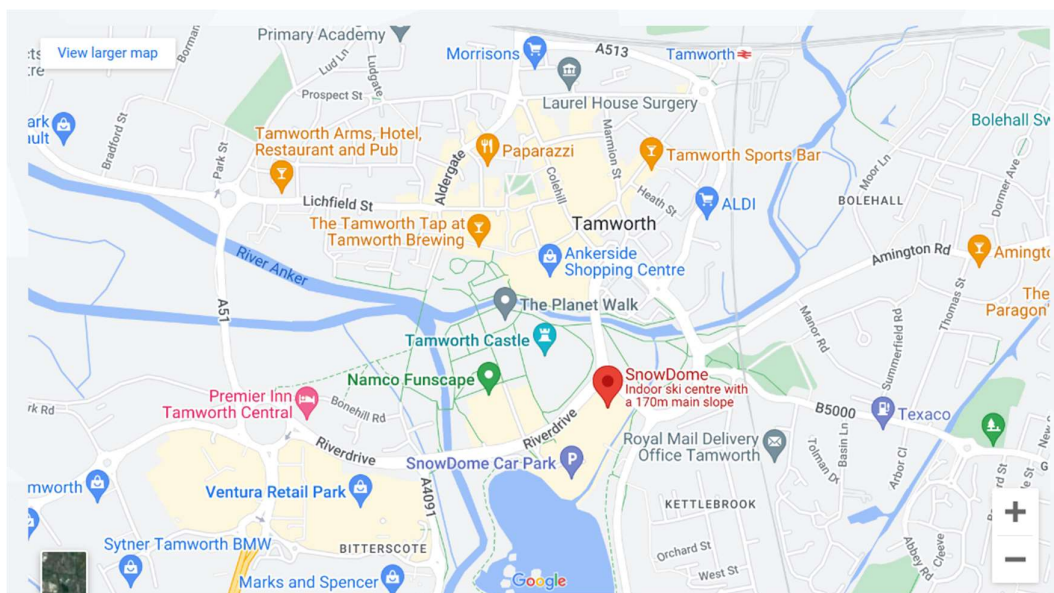
Travel information

Venue address

SnowDome Conference Facility, SnowDome, Leisure Island, River Drive, Tamworth (near Birmingham), Staffordshire, **B79 7ND**

Tel: +44 (0) 3448 000011 Guest Services & Bookings

Venue facilities and accessibility [more info](#)



By car

Postcode for navigation: **B79 7ND**

The SnowDome is easy to find and just 5 minutes from junction 10 of the M42 or M6 toll road.

- Follow all signs to Tamworth
- Lookout for the brown tourist information signs to the SnowDome
- There is ample parking at the SnowDome.
- Please note: **The Car Parking Fee is £2.50**

By train: **please be advised that train strikes are planned for the weekend of the event – find out more at: <https://www.thetrainline.com/trains/great-britain/industrial-action>**

- Tamworth Railway Station 0.9 miles
- Walking from Tamworth Railway Station:
 - Walk south down Saxondrive until the roundabout
 - Turn right onto Bolebridge Street
 - Then left onto Ankerdrive
 - SnowDome is at the south end of Ankerdrive
- Birmingham International Railway Station 18 miles

By plane

- Birmingham International Airport 18.1 miles
- East Midlands Airport 27.5 miles

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Accommodation information

Numerous hotels are situated within a short distance of the SnowDome, with plenty more a short drive away. There are hotels to fit all budgets and requirements. A selection are listed below:

| | | |
|--|-----------------|------------------------|
| Premier Inn Tamworth Central | 0.3 miles away | From £60-100 per night |
| Travelodge Tamworth Central | 0.25 miles away | From £45-100 per night |
| Drayton Manor Hotel | 2.5 miles away | From £110 per night |
| The Belfry | 7 miles away | From £209 per night |
| Moor Hall Hotel & Spa | 7 miles away | From £104 per night |

There are lots more hotels available in the area, an internet search will be able to help identify the facilities and types of hotel/budget that you may be looking for.

For information: *The BPA Committee will be staying at the Premier Inn, Tamworth Central Hotel.*

SnowDome activities/information

The SnowDome at Tamworth offers the ultimate snow, ice and leisure activities. A number of people from the BPA will be engaging in activities on the snow at the following times:

Lessons: Children 4-7 years old:

- Sunday 4 June
- 09:00-09:55
- Kinder Ski/Board Intro @ £28.00 per person

Lessons: Children and adults 8+:

- Saturday 3 June
- 13:00-15:00
- Ski/Board Level 1 (Intro/beginners class)
 - Junior Ski/Board 8-15 years @ £44.80 per person
 - Adult Ski/Board 16 years+ @ £51.80 per person

Please note: You need to book and pay for these activities directly with the venue *via their [bookings page](#)*

Clothing: Please also consider what clothing you may need to bring for such an activity – visit [SnowDome's website](#) for more information on [What to Wear](#).

Experienced snowboarders/skiers – if you are a competent snow user and would like to meet to engage in snow activities on the Sunday evening (after the BPA social), please get in touch ASAP.

If you have any questions about the activities and would like to speak with a member of the BPA team, please contact us: helpline@porphyria.org.uk or 0300 30 200 30.



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Accessibility information

The SnowDome Tamworth has step-free access and accessible toilets throughout the building. Please see [the venue's website](#) for more details on building access. Guidance on travelling to the venue is also available on their [Finding Us page](#).

Slides for the presentations will be made available after the event at the discretion of the speakers. The presentations will also be recorded and transcripts made available. If you would like to request slides to be sent to you after the event, please contact Liz or Sue at helpline@porphyria.org.uk.

Notes for those with EPP or other light sensitivities:

The SnowDome is a building with few external windows. The rooms in which the event will take place both have large internal windows that look out onto the SnowDome slopes, but no external windows. The lights can be turned down to suit attendees accordingly.

Note on Covid safety

We recognise that the Covid pandemic is ongoing. With a return to in-person events, it remains important to continue to take precautions to protect our communities, especially those most at risk of adverse effects from Covid such as those who are immunocompromised.

If you are able, please consider taking a rapid Covid test before attending, and please do not attend if you have Covid symptoms or have had a positive Covid test. Where relevant in these circumstances, we are happy to provide a refund on any donations made for the event – please just get in touch before the event at helpline@porphyria.org.uk.

We also welcome the wearing of face coverings at the event, however these are not mandatory. For more guidance on when to wear a mask or face covering, please see the most up-to-date [World Health Organisation guidelines](#).

Please also see the [SnowDome Tamworth website](#) for more information on the venue's Covid safety measures.

We strive to host inclusive, accessible events that enable all individuals to engage fully. To request an accommodation or for inquiries about accessibility that are not covered here, please contact helpline@porphyria.org.uk.

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Thank you

to our

2023 sponsors and supporters



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