

Many thanks to National Lottery players



BPA
CONNECT
Alfresco



And

disc)medicine

Welcome to the day

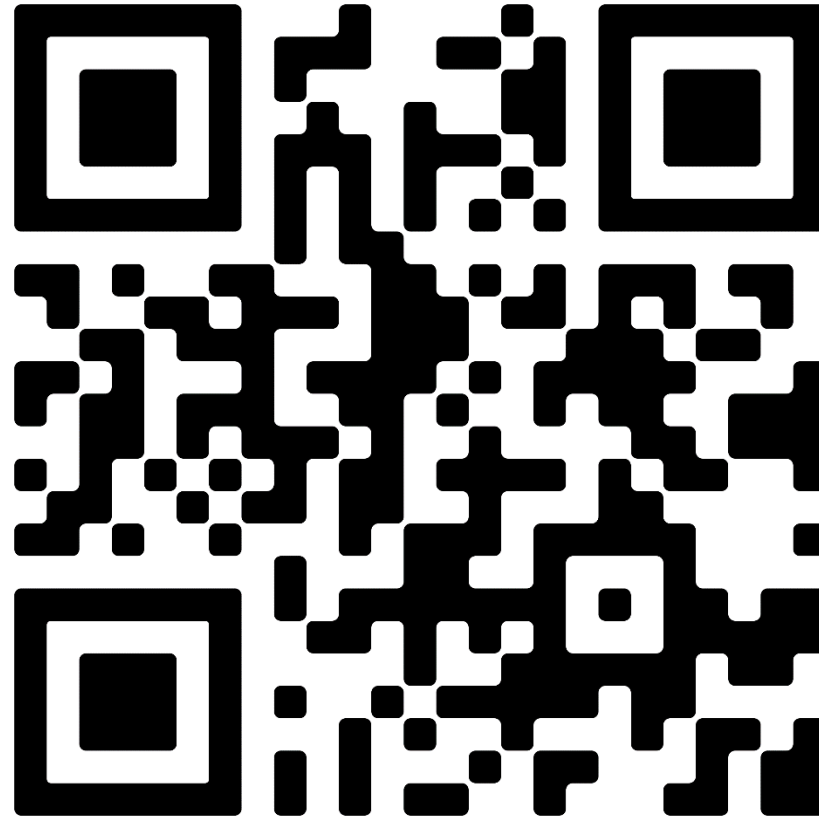
- Aims for the day
- Goodie bag and merchandise
- Plan for the day
 - Itinerary
- AGM
- Clueless introduction – Ian from Temple Newsam

BPA merchandise and fundraising

- Various merchandise
- Porphyria Awareness Week
- Christmas fundraiser
 - Baubles £6.00 each + £3.00 p&p
 - Christmas cards 3 packs for £10.00 + £3.00 p&p
- Sportifs...
 - Virtual London Marathon – Sun 23rd April 2023
 - Great North Run – Sun 10th September 2023

Itinerary and information pack

- Access here:



Plan for the day – Morning

Time	Activity	Who	Location
09:15	Registration and refreshments	All	Main House (Dining Room)
09:30	Welcome and AGM	All	Main House (Dining Room)
10:00	Set off to Go Ape to arrive before 10:15 Group A start	Group A Challenge and Adventure+	Go Ape
10:15	Set off to Go Ape to arrive before 10:30 Group B start	Group B Challenge and Adventure+	Go Ape
11:30	Clueless – see BPA in Still Room for guideline	All	Main House

For those awaiting/not joining/already completed a Go Ape session, take advantage of the time to explore the farm, the house, play area, parklands, or come join us in the LEGO workshop (Main House, Still Room)

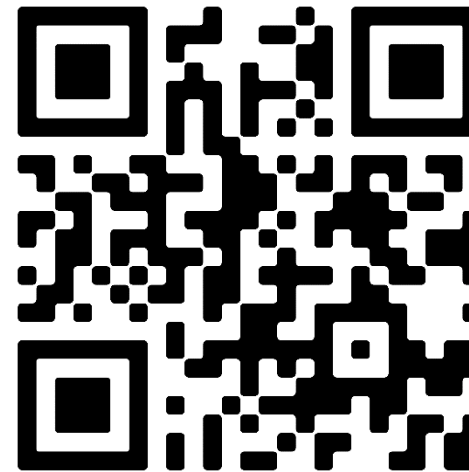
Plan for the day – Afternoon

Time	Activity	Who	Location
14:00	Group photo to thank National Lottery	All	Main House
14:05	Orienteering (ages 11-18) Treasure Hunt (10 and under)	11-18 years	Start from the house
14:45	Hide & Seek in the woods / Rounders		Woodland (see map)
14:45	Opportunity to explore the farm, the house, play area, parklands, or come join us in the LEGO Workshop (Main House, Still Room)		
15:45	Refreshments and farewell	All	Main House

Annual General Meeting – Agenda

- Apologies for absence
- Minutes of the last AGM
- Chairman's Report
- Treasurer's Report
- Election of Officers
- Date of next AGM
- AOB

Access BPA's
Annual Report 2022



Agenda

- Apologies for absence
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- Chairman's Report
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Annual General Meeting

- Apologies for absence
- Minutes of last AGM

Very pleased to be back to a face-to-face AGM after having had virtual AGMs in 2020 and 2021.

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Chairman's Report

2022 Updates

- Continue supporting patients through themes of UNDERSTAND, CONNECT and TAKE CONTROL
- Back to in-person events
- BPA Reconnect – June 2022: Live in Dundee and virtually streamed
- Continued focus on engagement and accessibility for young people – demonstrated by this event and the successful grant from National Lottery Community Fund

Agenda

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- **Chairman's Report**
- **Treasurer's Report**
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Chairman's Report

2022 Updates

- Continued focus on the mental health of people living with porphyria with your Wellbeing Project
- Demonstrated the patient experience in the approval of Givosiran with NICE – now available to patients
- Appointed a new volunteer Treasurer
- Seeking a new paid Administrator
- Continued focus on bringing in volunteers with specific skills
- Encourage and support research and continue to develop international networks

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Treasurer's Report

For 2021-22 Year

- Income: £23,062
- Expenditure: £23,111

Account name	31 Mar 2022	30 Sep 2022
BPA General Funds	£24,545	£23,336
Helen Gibbs Fund (restricted to research into acute porphyrias)	£17,197	£17,014
BPA Light Protection Fund (restricted)	£1,025	£1,020
Festival 2019 (restricted)	£1,197	£1,196

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Election of Officers

Formal election of Treasurer position

- Treasurer – Danil (Dan) Lopukhov

Other officers – happy to continue

- Chairman – John Chamberlayne
- Secretary – Richard Bennett

New Patron

- Vicky McGuire

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Thank you to our Working Groups

Fundraising & Awareness

Sue Burrell
Victoria Harrold
Natassja Chadwick
Alicia Cawthorne
Karen Harris
Anne Newton

Events

Antony Fearn
John Critchley
Richard Bennett
Sue Burrell
Liz Gill
Victoria Harrold

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And huge thanks also to our Duke of Edinburgh volunteer,
Parker Tapp

Date of next meeting

Birmingham – June 2023



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Any other business?

Clueless

Dining/Still Room – BPA can guide you

Main reception – Bags from Ian at Reception

Have fun 😊

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