

The British Porphyria Association

Annual General Meeting

Held via Zoom

3 October 2023

Committee attendees: John Chamberlayne (Chair & Trustee)
Karen Harris (Trustee)
Richard Bennett (Trustee & Secretary)
Natassja Chadwick (Trustee)
Anne Newton (Trustee & acting Treasurer)
Liz Gill (Strategic Lead of Operations and Advocacy)
Sue Burrell (Strategic Lead of Engagement and Advocacy)
Vicky McGuire (Patron)
Antony Fearn
Victoria Harrold
Claire Jarvis (Volunteer)

Apologies for Absence: Alan Molyneux (Trustee)

The meeting was opened by Sue Burrell who welcomed everyone to the AGM and gave a brief overview of the evening before handing over to John Chamberlayne to present the AGM.

Minutes of the last AGM

The minutes of the 2022 AGM held on 12 September 2022 were agreed. A copy of the 2022 AGM slides and minutes are attached. Also available at: [Policies and procedures - British Porphyria Association](#)

Chairman's and Treasurer's Reports

John Chamberlayne presented the Chairman's and Treasurer's reports as a prerecorded video. Slides highlighting both reports and finance figures are attached. John Chamberlayne also gave a summary of meetings and events attended in 2022.

Aims for 2023

Strategic aims and updates for 2023 were also given along with the dates for the forthcoming meetings and events for 2024.

Election of Officers

Votes were taken by a live online poll for the positions of chair, secretary and treasurer. John Chamberlayne, Chair, and Richard Bennett, Secretary are happy to continue. Danil Lupokhov, appointed Treasurer at the AGM in 2022 resigned in January 2023 due to personal reasons. Anne Newton stepped back into the role as acting treasurer whilst a new treasurer is appointed. All were unanimously re-elected.

Trustees

John Chamberlayne, Richard Bennett, Anne Newton, Karen Harris, Alan Molyneux and Natassja Chadwick were re-elected. Victoria Harrold and Dr Vicky McGuire expressed an interest in becoming trustees providing there are no conflicts of interest - this again was unanimously agreed.

AGM 2024

The date for the 2024 AGM will be September or October 2024.

Following the AGM Sue Burrell gave an overview of the BPAs exciting plans for 2024. The first being a meeting in Dublin in March 2024 and then Alfresco 2024 a residential activity weekend in Norfolk in October.

Representatives from the BPA will also be attending the International Congress of Porphyrins and Porphyrrias in Pamplona, Spain in September 2024.

To help finance Alfresco 2024, Sue explained that a fundraising campaign has been planned and is now underway to raise a collective pot of £20,000. To start this, a JustGiving campaign page has been set up at <https://www.justgiving.com/campaign/empoweringporphyriapatient>. Some suggestions for raising funds was to get involved with #SpotlightPorphyria or #PurpleforPorphria. Get your work/school/community involved to raise awareness of porphyria and the work the BPA do by arranging a wear #PurpleforPorphyria day and donate £1.00 to the BPA at any point in the year or on Global Porphyria Day (18 May 2024) or Rare Disease Day (29 February 2024).

Breakout Rooms

The attendees were then given the opportunity to join one of three discussion groups. One for acute porphyrias, one for cutaneous porphyrias and the third for families interested in attending the residential weekend.

The breakout rooms gave attendees the opportunity to speak to others with an interest in a specific type of porphyria, and families interested in the residential event in 2024 to find out more.

At the close of the breakout rooms, Sue Burrell thanked everyone for attending and closed the meeting.