

The British Porphyria Association
Annual General Meeting
Held via Zoom
Monday, 30 September 2024: 18:00-18:30

BPA team attendees

John Chamberlayne (Chair & Trustee)
Claire Jarvis (Treasurer & Trustee)
Natassja Chadwick (Trustee)
Anne Newton (Trustee)
Liz Gill (Co-CEO)
Sue Burrell (Co-CEO)
Vicky McGuire (Trustee – incoming Chair)
Victoria Harrold

Apologies for absence

Alan Molyneux, Karen Harris, Antony Fearn, Richard Bennett

Minutes of the last AGM

The minutes of the 2023 AGM were agreed. A copy of the 2023 AGM slides and minutes are attached. Also available at: <http://porphyria.org.uk/policies-and-procedures/>

Chair's Report

After thanking those in attendance for joining, the Chair directed attendees to the summary AGM report (available on the [website](#)). Chair reported on 2023 and 2024 events and provided a summary of day-to-day operations taking place, as well as team changes:

- John Chamberlayne stepping down as Chair and Dr Vicky McGuire volunteering as new Chair
- Officially welcoming Claire Jarvis to role of Treasurer/Trustee (1 April 24)
- Richard Bennett stepping down as Secretary
- Georgia Newman has an updated role title of Fundraising & Communications Officer
- Continued focus on bringing in volunteers with specific skills, where we welcomed Jenny Kirk, Kathryn Wilson and Pete Carter to our volunteer pool.

Treasurer's Report

The BPA Treasurer reported on income and expenditure for the financial year to 31 March 2024, where income was £38,654 and expenditure was £44,162. She provided a breakdown of income generation and likely sources going forwards, as well as highlighting how expenditure takes place across the organisation See slides and report attached.

Election of Officers

Votes were taken by a live online poll for the positions of chair, secretary and treasurer. Dr Vicky McGuire was unanimously accepted as the new Chair. Claire Jarvis was formally voted on as the new Treasurer. Richard Bennett resigned from post, seeking new Secretary.

John Chamberlayne, Richard Bennett, Anne Newton, Karen Harris, Alan Molyneux, Natassja Chadwick, Victoria Harrold and Dr Vicky McGuire were re-elected as trustees.

Changes to the Constitution

A letter and email was sent to all members in the week commencing 1 September 2024 to propose a number of changes to the Constitution. Proposed changes were unanimously agreed. Changes included:

- Language that better reflects our day-to-day usage, as well as gender neutral language
- Defining what we focus on more accurately, by adding words such as quality of life, financial security and mental health
- Updates relating to the way we work, eg digital working and virtual events

Future plans

The team outlined that in 2024 so far, the BPA distributed 400 CYACELLE bottles donated by Clinuvel, hosted two peer support sessions, and attended the International Congress on Porphyrins and Porphyrrias. The team has supported patients with Blue Badge, PIP and Access Card applications, and secured funding to maintain organisational stability.

Looking ahead, BPA will continue to support patients through the core themes of *Understand, Connect, Take Control* and *Share*. Planned activities include the Connect Alfresco residential in October 2024, a face-to-face meeting in March 2025, and regular peer support sessions throughout 2025. The organisation will also focus on improving engagement and accessibility, strengthening resilience through a new database, collaborating with researchers and pharmaceutical partners, and expanding patient resources including factsheets, information materials and videos.

Date of next AGM

September or October 2025

No other business. The AGM was officially closed at 18:30 and attendees were invited to join the peer support sessions which were due to run afterwards.