THE BRITISH PORPHYRIA ASSOCIATION

Report from the Chair

The 2023-2024 financial year was a productive period for our team. We continued to advocate for, support, and educate porphyria patients, their families, and medical professionals. This year, we expanded our themes of support to include SHARE alongside CONNECT, UNDERSTAND, and TAKE CONTROL.

Porphyria awareness and events
Global Porphyria Day on 19 April 2023 saw widespread engagement worldwide. The theme "This Is My Porphyria" encouraged participation from patients and their families.

Our in-person patient conference in Tamworth in June 2023 was a highlight, providing networking opportunities and informative sessions with UK porphyria experts. The BIPNET (British & Irish Porphyria Network) Annual Conference followed, enhancing collaboration and knowledge exchange between our team and medical professionals.

Although our planned residential event in September 2023 was postponed until Oct 2024, we held a successful virtual AGM in October 2023, which included an online social gathering for community input on future activities. Two attendees at the AGM, Dr Vicky McGuire and Victoria Harrold, were appointed as trustees after being involved with the charity for numerous years.

In March 2024, we returned to Dublin for a Patient Day supported by St James's Hospital and BIPNET, featuring patient and doctor talks, research updates, and Q&A sessions. We also launched our first online Peer Support Group Drop-In Session. The success of this has seen it become a regular feature in our BPA schedule of events.

BPA Team
As we continued to work towards strengthening our team and our resilience for the future, in March 2024 we welcomed Claire Jarvis as our new Treasurer and Trustee. Continued work from Georgia, our Fundraising & Communications Officer, saw our social media presence grow significantly, with a 56% increase in content interaction and a 53% rise in followers compared to the previous year. We have been working to engage more volunteers in our work and we are thrilled to welcome Jenny Kirk, Kathryn Wilson and Pete Carter to our volunteer pool.

As I step down as Chair, we are delighted to welcome Dr Vicky McGuire as the new Chair. Vicky brings a wealth of scientific experience and a fresh perspective to the BPA. We are confident that under her guidance, we will continue to achieve our goals to advance awareness, support, and research in the porphyria community.

Please join us in welcoming Vicky to her new role.

John Chamberlayne

2024 ANNUAL AGM REPORT

Treasurer's Report

The accounts were examined by Jane Ascroft Chartered Accountancy Limited, Barnard Castle.

Account name	31 Mar 2024	20 Sep 2024
BPA General Funds	£14,201	£48,289
Helen Gibbs Fund (restricted to research into acute porphyrias)	£17,038	£17,165
BPA Light Protection Fund (restricted)	£ 902	£ 457
Festival 2019 (restricted)	£ 1,214	£ 1,222

2023-24 FINANCES

Income

£38,654

Expenditure

£44,162

BPA income in 2023-24 was £38,654, while expenditure was £44,162. As can be seen from the bank balance at 20 Sept 24, we have been successful in rebuilding our reserves fund back to a more comfortable level at around 6-8 months of expenditure. The General Funds of £48,289 will be depleted in the coming weeks by around £10,000 following expenses due for the Alfresco Weekend.

Income during the financial year was made up from donations, fundraising and sponsored events, merchandise sales, grants and sponsorship (see Fig 1).

Thank you to all who have made donations and have raised funds for the BPA. We really couldn't continue to do the work that we are doing without these amazing efforts.

Our corporate supporters, Alnylam Pharmaceuticals, Disc Medicine, Mitsubishi Tanabe Pharma Company, Clinuvel UK, and Alpkit Foundation helped to support our events and attendance of key BPA personnel. Their sustained assistance enables us to continue helping and supporting porphyria patients and their families through valued BPA events and opportunities to gain further knowledge.

Expenditure for the 2023-24 year was £44,162 (see Fig 2 for a breakdown). The highest costs relate to administration fees and event costs. The costs incurred for the Dublin meeting in March 2024 came out in the 2023-24 financial year, whereas the grants and sponsorship provided to cover the event costs did not reach the BPA bank account until the 2024-25 financial year, hence the higher level of expenditure than income in 2023-24.

During the current financial year, 2024-25, we have secured funds to maintain business as usual operations and support our other 2024 events, including a residential for young people with EPP, and attendance of the BPA at the International Conference on Porphyrins and Porphyrias (Pamplona). In addition to the corporate supporters noted above, we are delighted to thank the National Lottery Community Fund, SSIEM, BetterHelp and Coolibar for their amazing support.

Monies in the Helen Gibbs Fund continue to be allocated to the handful of AHP patients each year who are eligible to receive Givlaari but are unable to cover the cost of travelling to a porphyria centre for the first six months. Discretionary grants are also provided where needed to support families with costs incurred due to their porphyria.

Fig. 1

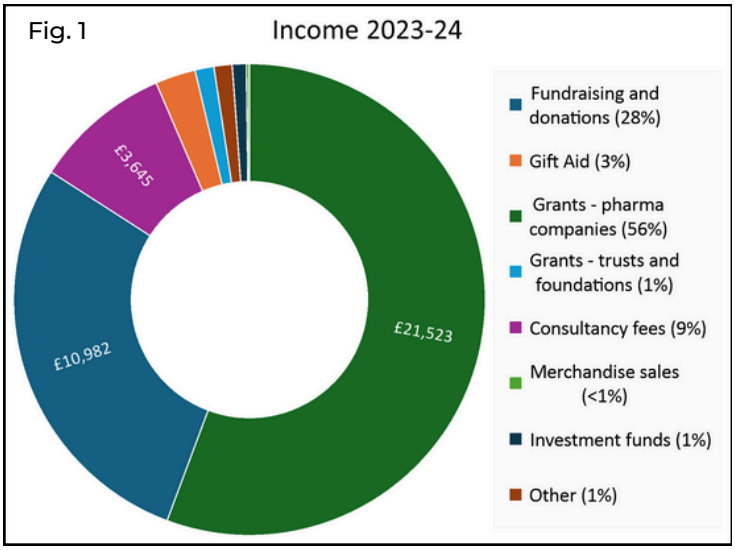


Fig. 2

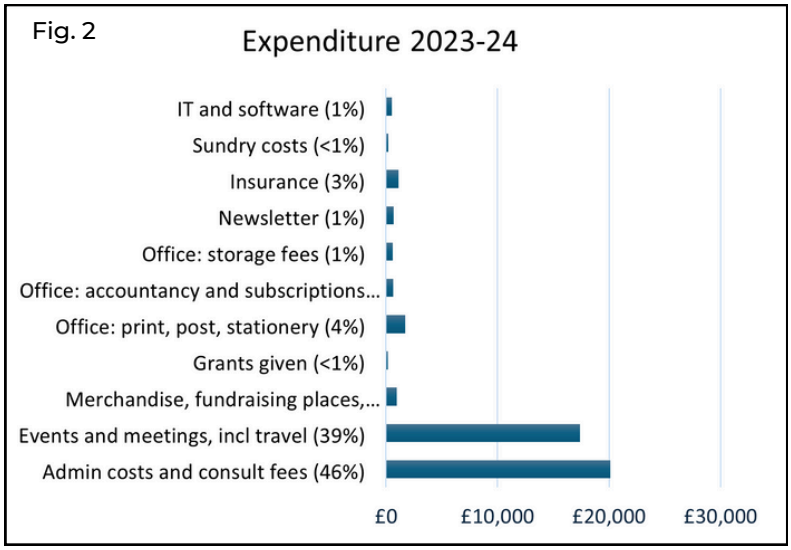
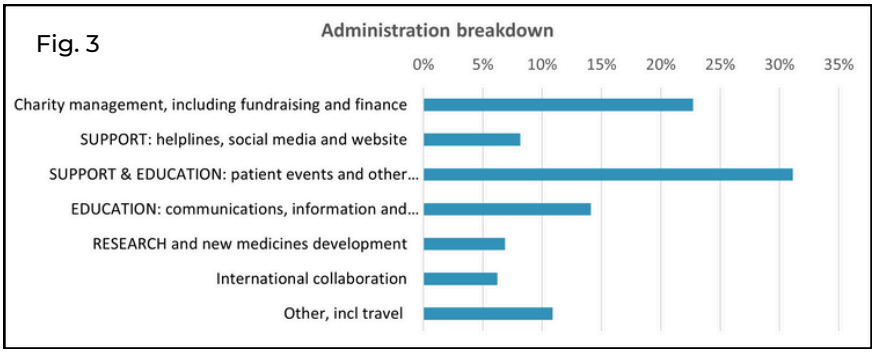


Fig. 3



What do we do?

Administrative costs are a large part of our expenses. Fig. 3. shows our paid administrators split their time and how this work supports our aims.

Additionally, our volunteers have a huge impact on our ability to serve the porphyria community. Without them, we wouldn't be able to provide the support that we do. Thank you to you all.