



# THE BRITISH PORPHYRIA ASSOCIATION



## Chairman's Report

The 2022-2023 financial year was a busy year. Our helplines, social media platforms and website continued to offer support to the porphyria community, but we were especially delighted to be able to resume face-to-face contact with our members again after Covid.

In May 2022, a successful BPA RECONNECT was held in Dundee with over 40 people attending in person and many more online in our first venture into a hybrid patient event. In September 2022, representatives from the BPA attended the International Congress on Porphyrins and Porphyrins (ICPP) in Sofia, Bulgaria and the ICPP Patient Day. The congress brought together the whole porphyria community of patients, patient advocates, scientists, treating physicians, researchers and pharmaceutical partners to share learning on porphyria.

Later in 2022, an award of £9,500 from The National Lottery Community Fund and a grant from Disc Medicine enabled us to hold BPA Connect Alfresco at Temple Newsome in Leeds. This event brought together families affected by EPP from across the UK and Ireland. It fulfilled a long-term BPA aim to provide a safe outdoor physical activity day for children and young people with the support of those with knowledge and experience of EPP.

During the financial year, we continued to take an active part in appraisals of new treatments and maintained our involvement with researchers and companies exploring potential treatments to ensure the patient voice was considered at the early stages of research and throughout the process.

Towards the end of the 22-23 financial year, Danil Lopukhov, our new treasurer and trustee, resigned due to work commitments. Once again, Anne Newton temporarily took on the responsibility as Acting Treasurer while a new Treasurer is found. We wish Danil well in the future and continue to seek a new treasurer.

Dr Vicky McGuire, Principal Clinical Scientist working at the Scottish Cutaneous Porphyria Service in Dundee became a BPA patron at our last AGM and is an active member of our volunteer team.

During the 2022-2023 year, our committee looked closely at the resilience of the administrative team of the BPA and advertised for a new admin assistant to help distribute the workload. We were delighted to welcome Georgia Newman in March 2023, working 20 hours a month. We also welcomed a new volunteer administrator for 12 months, Claire Jarvis. Together Claire and Georgia have already had a substantial positive effect on moving the charity forwards.

Thank you to Claire and Georgia, as well as our fantastic team of fundraisers, supporters, patrons, trustees, committee and working group members, who continue to support the work that we do.

*John Chamberlayne*

## 2023 ANNUAL AGM REPORT



[www.porphyria.org.uk](http://www.porphyria.org.uk)

helpline@porphyria.org.uk 0300 30 200 30

Registered charity: 1089609

# Treasurer's Report

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

**2022-23  
FINANCES**

Income

**£43,549**

Expenditure

**£48,132**

Account name	31 Mar 2023	28 Sep 2023
BPA General Funds	£20,274	£11,830
Helen Gibbs Fund (restricted to research into acute porphyrias)	£16,885	£16,964
BPA Light Protection Fund (restricted)	£1,022	£1,204
Festival 2019 (restricted)	£1,200	£913

With the recommencement of face-to-face events, our income and expenditure saw a return to higher levels in 2022-23. Income of £43,549 was primarily made up from donations, Gift Aid and grants, including £9,500 from the National Lottery Community Fund (see Fig 1). The sustained assistance of our sponsors enables us to continue helping and supporting porphyria patients and their families through valued BPA events and opportunities to gain further knowledge. However, none of this would be possible without our fundraisers and donors, and we would like to thank all those 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.

Expenditure for 2022-23 was £48,132 (see Fig 2 for a breakdown). The highest costs related to administrative fees (see Fig 3) and events. These costs included travel bursaries for the Alfresco event to enable it to be accessible to all - including two families from Ireland.

Monies in the Helen Gibbs Fund continue to be used for 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 of treatment.

The September balance excludes a grant of £10,000 which was secured from Alynham in June 2023, but has still to be received by the BPA.

During the 2023-24 financial year, we will be seeking funding to enable us to focus on strengthening and protecting our core organisational resilience, as well as launching a new fundraising campaign with a target of £20,000 to support our residential event for young people with EPP in Thetford (12-13 October 2024). We will continue to provide a grant process and travel bursary to assist members with individual needs or with additional costs due to their porphyria.

Fig. 1 Income 2022-23

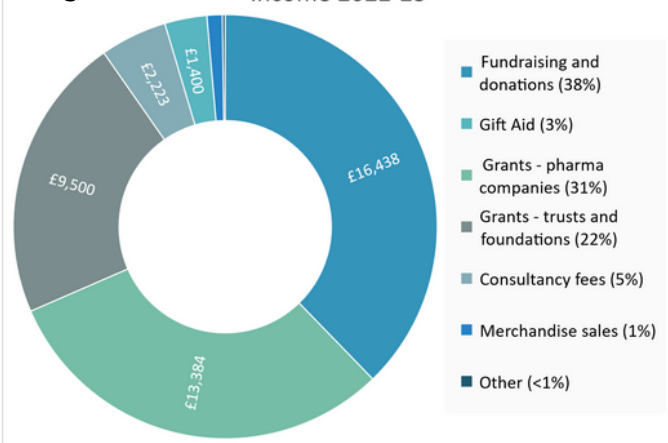


Fig. 2 Expenditure 2022-23

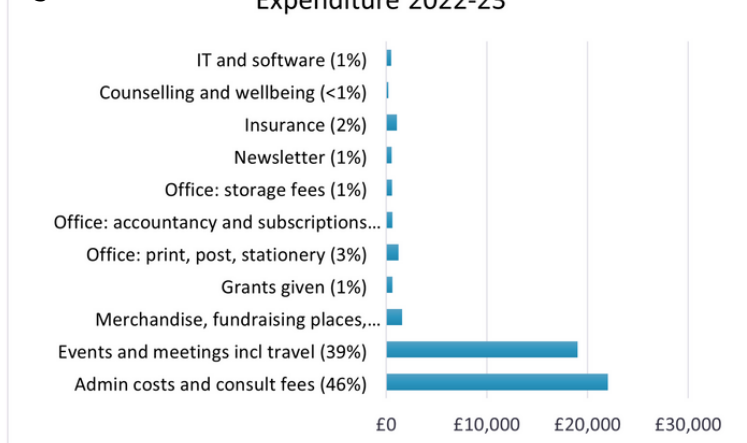
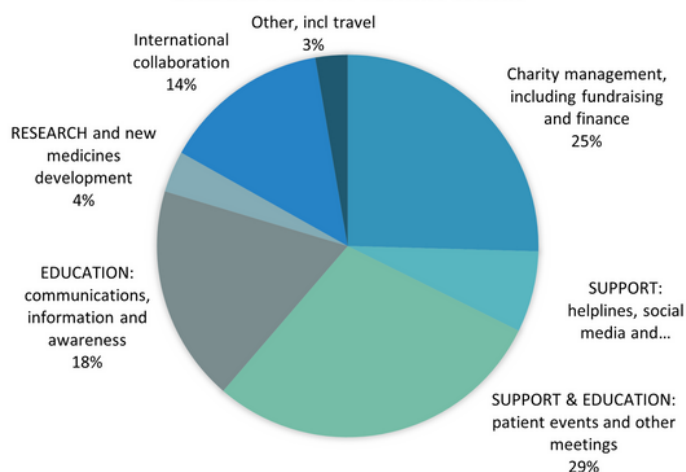


Fig. 3

## BREAKDOWN OF ADMIN WORK



## What do we do?

Administrative costs are a large part of our annual expenditure. Fig. 3. demonstrates how our paid administrators split their time and how this work supports our aims of EDUCATION, SUPPORT, RESEARCH & ADVOCACY.

Our volunteers also have a significant impact on our ability to serve the porphyria community. Without our dedicated volunteer committee, we wouldn't be able to provide all of the support that we do.