THE BRITISH PORPHYRIA ASSOCIATION

www.porphyria.org.uk
0300 30 200 30
Charity 1089609

Report from the Chair

The past year has been an exciting and productive time for the BPA and the porphyria community, marked by a range of impactful events and initiatives to support those affected by porphyria.

Community events and engagement: our Peer Support Programme, launched in 2024, continued with further sessions in late 2024 and early 2025, offering all ages and families a space for understanding, connection and confidence.

The Connect Alfresco Residential 2024 in Norfolk was a landmark event, bringing together 15 families for a weekend of safe outdoor activities, counselling and support under tree cover. The success of this event, captured in two awareness films — *Empowering People with Porphyria* and *We're Not Alone* — highlighted the value of community connection and will inform future programmes.

The BPA also participated in the 2024 International Congress on Porphyrins and Porphyrias (ICPP) in Pamplona, gaining key insights into global research and treatments. The 2025 BPA Patient Conference, held at the National Museum of Wales, united professionals, patients and researchers, reaching many new members of the community. The BPA also contributed to the BIPNET Annual Meeting, reinforcing shared goals across the UK and Ireland.

Advocacy and support: The BPA continues to advocate for new treatments, ensuring patient perspectives are represented throughout research and regulatory processes. Our phone and email helplines remain essential to one-to-one patient support, complemented by newsletters and growing social media engagement — with a 46% rise in interaction this year thanks to the efforts of Communications Officer Georgia Newman.

Fundraising remained strong through Rare Disease Day, Global Porphyria Day, and our Christmas campaign. We are deeply grateful for the community's continued generosity, as well as ongoing sponsorships and successful grant applications.

Through our discretionary grant scheme, the BPA continues to assist patients with medical and travel costs, including support via the Helen Gibbs Fund for acute porphyria patients undergoing Givlaari treatment.

International and strategic work: the BPA plays an active role in international networks. Liz Gill completed her six-year term on the Ipnet Executive Board and continues in working groups for acute porphyria and expert centres. Vicky McGuire was elected Treasurer of Ipnet and remains active in clinical network workstreams, while Sue Burrell continues as President of the Global Porphyria Advocacy Coalition (GPAC).

A strategy meeting in June 2024 set priorities for 2025-2027, and leadership changes saw Dr Vicky McGuire become Chair and Victoria Harrold take on the Secretary role, following decades of service by outgoing Chair and Secretary John Chamberlayne and Richard Bennett.

2025 highlights and future planning: this year included our first-ever Global Porphyria Day raffle, new patient awareness videos, distribution of donated sunscreen, participation in global research studies, and presentations at major international conferences. We are also investing in BPA's future by exploring new CRM systems, pursuing long-term funding, and expanding our volunteer and trustee teams — including welcoming Antony Fearn as a trustee.

It has been a rewarding year working alongside our dedicated co-CEOs, Liz Gill and Sue Burrell, our trustees, and volunteers. The BPA continues to grow in strength and impact, and we look forward with optimism and determination to what lies ahead for the porphyria community.

Dr Vicky McGuire

2025 ANNUAL AGM REPORT

Treasurer's Report

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

Account name	31 Mar 2025	30 Sep 2025
BPA General Funds	£47,420	£49,315
Helen Gibbs Fund (restricted to research into acute porphyrias)	£17,290	£16,938
BPA Light Protection Fund (restricted)	£1,385	£2,023
Festival 2019 (restricted) Re named Restricted Fund	£1,232	£5.00

2024-25 FINANCES

Income

£86,063

Expenditure

£52,609

BPA income in 2024-2025 was £86,063, expenditure was £52,609.

As of 2 October 2025, the total funds held is £68,555, of which £49,587 is in unrestricted funds, and £18,967 in restricted funds.
Income was made up from donations, fundraising and sponsored events, merchandise sales, grants and sponsorship (see Fig 1).
The work of the BPA can only continue with the amazing efforts of our supporters and fundraisers, who have this year organised Bingo parties, Race nights, Dungeons & Dragon evenings, baked and eaten cake, shaken buckets, run marathons, walked in kilts and climbed mountains!

We were honoured to receive a substantial legacy in the memory of Margaret (Peggy) Seary, who had AIP, was a long-time supporter. We were deeply touched by the generosity of Peggy and her family for thinking of the BPA with such a meaningful act of kindness.

Our corporate supporters, Alnylam Pharmaceuticals, Mitsubishi Tanabe Pharma Company, Clinuvel UK, and Portal Therapeutic helped support BPA events and enabled key BPA personnel to attend International Porphyria related conferences. Their increased and sustained assistance enables us to continue helping and supporting porphyria patients and their families. A substantial grant from the National Lottery Community Fund, enabled us to fund the Alfresco 2024 event.

Expenditure for the 2024-25 year was £52,609 (see Fig 2). The highest costs relate to administration fees and event costs.
The Helen Gibbs Fund has been and will be continued to be used to support a limited number of AHP patients who are eligible for Givlaari but face challenges in covering travel expenses to a porphyria centre during the initial six months of treatment. Discretionary grants will also be provided where needed to support families with costs incurred due to their porphyria

Fig. 1

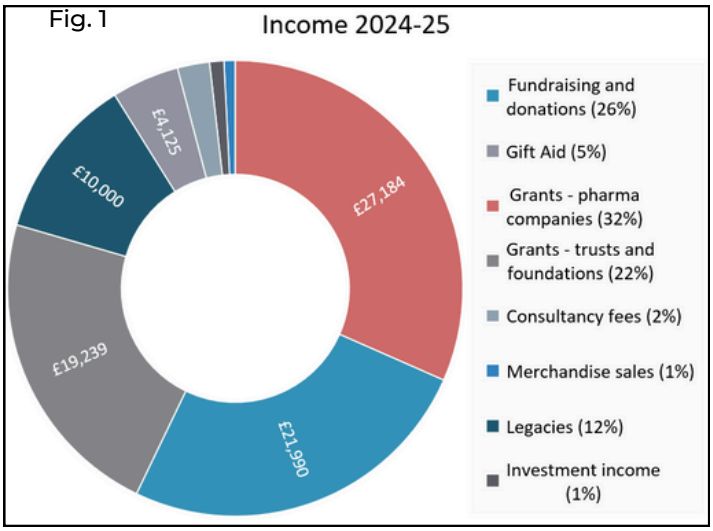

Fig. 2

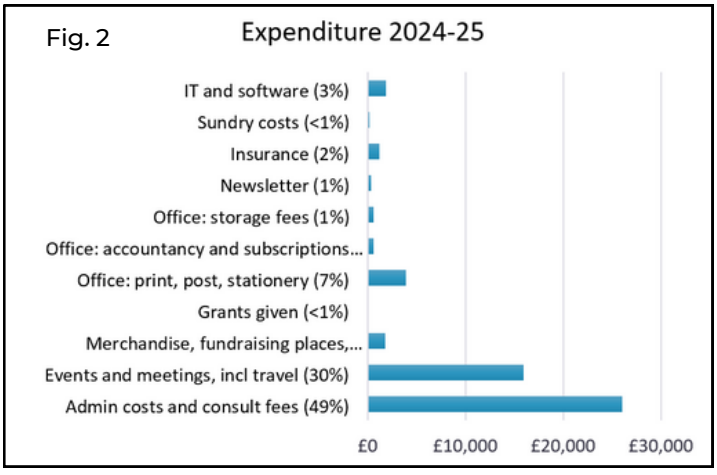

Fig. 3