



THE BRITISH PORPHYRIA ASSOCIATION



Chairman's Report

The 2021-22 financial year was another productive year for the BPA, with many ongoing projects, despite the impacts of the Covid-19 pandemic still being felt across the community.

Our helplines, social media platforms and website continued to offer support to the porphyria community, but with uncertainty remaining around face-to-face events, we held our annual patient event virtually in October 2021. The webinar combined our AGM, a focus on the new drug development process, the importance of research, patient journeys, and counselling and wellbeing sessions. In addition to connecting with our UK porphyria community, participants from all over the world joined us on the day.

We played a vital role in demonstrating the patient experience in the appraisal of new treatments for porphyria. In October 2021, a new treatment for severe acute porphyria, Givlaari, was approved for use on the NHS in England. Patients started to receive the treatment in late February 2022.

During 2021-22, we secured funds for our Wellbeing Project and during 2022 we started to put the second stage of this project into action, with a patient in need taking up the offer of a series of counselling sessions with a trained counsellor. This project will continue to support patients where needed.

Towards the end of the 21-22 financial year, we appointed Danil Lopukhov (Senior Finance Business Partner for Merck UK) in the position of Volunteer Treasurer for the BPA. The start of the 2022-23 financial year has seen Dan settling into his new role. We are confident that his experience and expertise will be a great asset to the charity.

We will maintain our aim to support families affected by porphyria through our themes of UNDERSTAND, CONNECT and TAKE CONTROL. But we couldn't do this without our amazing team of fundraisers, supporters, trustees, committee and working group members, who put in countless hours to keep the charity moving forwards.

Thank you all for your continued support.

John Chamberlayne

2022 ANNUAL AGM REPORT



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.

2021-22 FINANCES

Income
£23,062

Expenditure
£23,111

Account name	31 Mar 2022	30 Sep 2022
BPA General Funds	£24,545	£23,336
Helen Gibbs Fund (restricted to research into acute porphyrias)	£17,197	£17,014
BPA Light Protection Fund (restricted)	£1,025	£1,020
Festival 2019 (restricted)	£1,197	£1,196

Despite Covid reducing the number of fundraising opportunities in the 2021-22 year, our income and expenditure continued to remain stable. Income (£23,062) was made up of donations, grants, Gift Aid, merchandise sales and monies received from fundraising events (Fig. 1).

Expenditure for 2021-22 (£23,111) included a £1,000 contribution towards a research project carried out by the Scottish Cutaneous Porphyria Service to examine whether a regularly used medication (Dapsone) was associated with increased levels of protoporphyrin in blood (and the development of EPP symptoms). Funds continue to be used for administration, printing, postage, insurance, newsletters and more (Fig. 2).

The September 2022 balance includes a grant from the National Lottery Community Fund (£9,500) to support today's Connect Alfresco event for our young porphyria community. Some expenses for the event are still to be accounted for. The September balance excludes a grant of £10,000 which was secured from Alnylam in May 2022, but has still to be received by the BPA.

We continue to provide a grant process and travel bursary to assist members with individual needs or with additional costs due to their porphyria. We were delighted to be able to allocate a pot of funds to assist some patients to cover the cost of essential travel to a porphyria centre for the first six months of Givlaari treatment, after which they will receive it via homecare.

Fig. 1

Income 2021-21

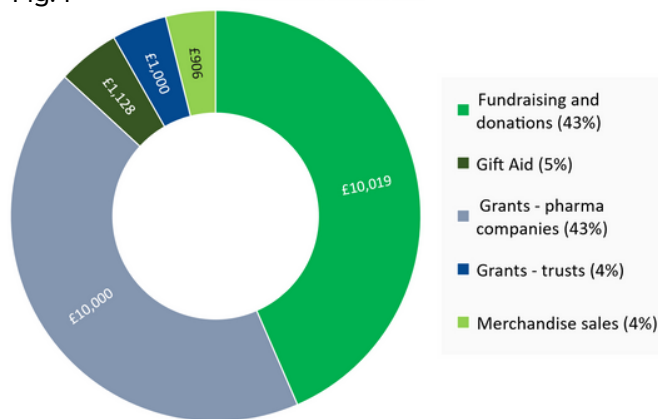


Fig. 2

Expenditure 2021-22

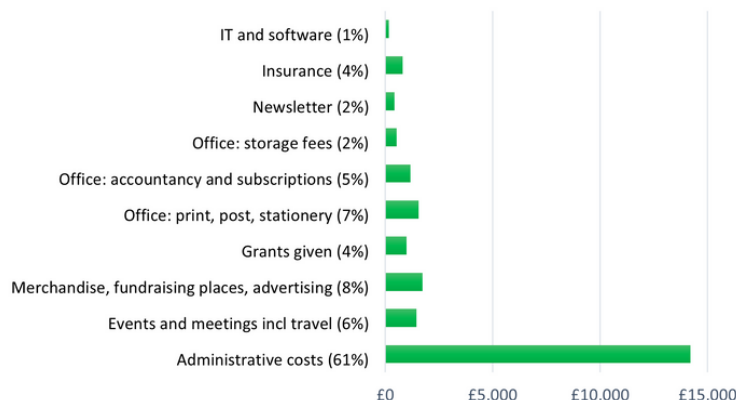
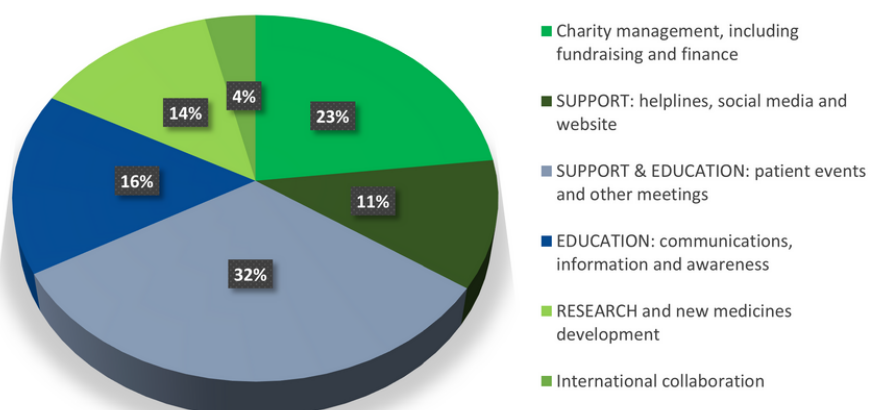


Fig. 3

Admin costs - time allocation



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 and RESEARCH.

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.