

The British Porphyria Association
Financial Statements
For the Year Ending
31 March 2025

JANE ASCROFT ACCOUNTANCY LIMITED

Chartered Accountants
Enterprise House
Harmire Enterprise Park
Barnard Castle
County Durham
DL12 8XT

The British Porphyria Association

Financial Statements

Year Ended 31 March 2025

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The British Porphyria Association

Trustees' Annual Report

Year Ended 31 March 2025

The trustees present their report and the unaudited financial statements of the charity for the year ended 31 March 2025.

Objectives and Aims

The charity's objectives are the relief of sickness and the protection and preservation of the health of persons affected by Porphyria and any related condition and their families and carers, in particular by, but not restricted to:

- a) The advancement of the education of the medical profession and the general public into Porphyria and its implications for the family.
- b) The promotion of research into the causes, effects, treatment and management of Porphyria and to disseminate the useful results thereof.

Activities and Achievements

The 2024-2025 financial year was superbly busy. We continued to work towards our aims to advocate for, support and educate porphyria patients, relatives and medical professionals, to improve the quality of life for those living with the different types of porphyria. We continued to promote awareness and the advancement of research into new therapies.

We expanded our themes of support by adding SHARE to our themes of CONNECT, UNDERSTAND and TAKE CONTROL.

Porphyria Awareness

Porphyria Awareness Week ran from 11 - 18 May 2024, with Global Porphyria Day (GPD) being celebrated on 18 May 2024.

The week provided the opportunity to engage in awareness and fundraise about porphyria as well as opportunities for patients and their families and friends to share insight into Porphyria via the hashtags #MyPorphyria, #SpotlightPorphyria and #PurpleForPorphyria. A toolkit of resources was added to the website to assist and encourage people to take part this included template letters and posters.

The British Porphyria Association

Trustees' Annual Report *(continued)*

Year Ended 31 March 2025

Conferences And Events

In June and September 2024, online Peer Support Group Drop-In Sessions were held to support patients with EPP/XLP and other porphyrias. The sessions were open to all ages, and families affected were encouraged to attend together. This is a programme of support that aims to help people living with porphyria to understand their condition, connect with others and build the confidence to take control and share their story to help promote porphyria awareness. Our 2024 AGM was held in conjunction with the September Peer Support session.

On 8 June 2024 the BPA held a Strategy meeting in Newark, attended in person by the CEOs, Chair, Trustees and volunteers. The purpose of the meeting was to review the overarching aims of the BPA, feedback on projects and review outcomes of the past 12 months. The second half of the day was spent on creating a strategic plan and prioritising the focus points for the charity for 2025 to 2027.

In October 2024 the BPA held the first Alfresco Residential for those affected by EPP and XLP at Thorpe Woodlands, Norfolk.

Making use of protective clothing and the excellent tree cover, 15 families affected by EPP/XLP from across the UK and Ireland, were able to avoid the sun and concentrate on the most important things - connecting with others with porphyria and participating in outdoor-based events and activities that they would not normally consider to be possible. Activities included climbing, zip-wires, tree top walks, fan drops, archery and caving.

The BPA also facilitated a Q&A session for parents of the participants, featuring the Chair and CEOs of the BPA, and offered one-on-one counselling sessions with an accredited counsellor for those seeking individual support.

The event was filmed by a volunteer videography team who, as well as filming the activities, also interviewed the young people taking part and their parents and siblings to gain an insight into the impact of living with EPP. The footage has been used to create two videos. One video 'Empowering people with porphyria' captures the atmosphere and impact of the day, offering a glimpse into the vital work the BPA is doing and the importance of bringing people together. The second video, 'We're not alone' shares a deeply personal story of living with EPP, told through the eyes of Tiernan and Niamh, a family navigating life with this rare condition. Further footage will be used in the coming months to create informative videos about living with EPP for future awareness campaigns.

In total 52 people attended the event, comprising of: 7 x BPA staff/volunteers (3 x EPP), 4 x EPP Defenders/volunteers - who were there to support the children and young people with EPP/XLP, 15 x EPP families/households, 4 x Videographers (2 x EPP) and 1 x Counsellor.

This event was made possible thanks to the generous support of our fundraisers, as well as support from the National Lottery Community Fund, the Alpkitt Foundation, the Society for the Study of Inborn Errors of Metabolism (SSIEM), Mitsubishi Tanabe Pharma Company, Clinuvel Pharmaceuticals Ltd, Disc Medicine, Alnylam Pharmaceuticals and Coolibar Sun Protection Clothing.

The aim of the weekend was to empower young people with EPP/XLP to help them understand their condition, connect with others with EPP/XLP, build the confidence to take control, and share their story. Survey results and informal feedback indicated that this aim was successfully achieved. By bringing together children, young people, and parents affected by these conditions, the event fostered meaningful connections and lasting friendships-both among individuals with EPP/XLP and among their parents-that continue to flourish.

The BPA is extremely proud to have facilitated a weekend full of connection, support, and encouragement, and to have created a unique space to strengthen this vibrant community.

The 2025 Patient Conference was held on Saturday 29 March 2025 at the National Museum of Wales in Cardiff. Attendees included medical professionals from Cardiff, Dundee and London, individuals

The British Porphyria Association

Trustees' Annual Report *(continued)*

Year Ended 31 March 2025

with lived experience of porphyria, patients and their families, industry representatives, and international researchers. The event provided a valuable platform for knowledge exchange, with opportunities for learning and peer support.

Importantly, the conference reached newly diagnosed patients and individuals not previously known to the BPA, enabling us to extend our support to a broader community. This represents a significant outcome in addition to the day's wider benefits.

The previous day, members of the BPA team participated in the BIPNET (British & Irish Porphyria Network) Annual Conference, contributing to discussions and presentations. This ongoing collaboration between BIPNET and the BPA continues to strengthen the shared aims of education, best practice, and mutual support across the porphyria community.

International Events

The BPA were represented at ICPP2024 in Pamplona (Spain) between 21-25 September 2024, by Liz Gill (co-CEO), Sue Burrell (co-CEO) and Vicky McGuire (Chair). This was the biggest International Congress of Porphyrins and Porphyria's held to date. They attended talks and gathered information on topics ranging from porphyria awareness to diagnosis, treatments, patient support and the long-term complications of living with porphyria. Reporting back to the BPA they shared that there was a real sense of excitement and positivity for the future of porphyria treatments and gave updates on existing medications as well as newer drugs entering clinical trials.

BPA Team

John Chamberlayne and Richard Bennett stood down from their positions of BPA Chair and Secretary respectively having served the BPA for more than 20 years, they both remain as Trustees.

Dr Vicky McGuire has taken on the BPA Chair role, and Victoria Harrold the role of Secretary.

Website, Social Media & Helplines

With the continuing support our fundraising and communications officer, the BPA have continued to broaden our reach and interaction on social media. Content interaction saw a 46% increase on the prior year and our reach increased by a further 3%.

Twice yearly newsletters were produced and sent out to our members, where BPA funds were used for administration fees, printing and postage. A successful Christmas fundraising campaign was held again in 2024, selling Christmas cards and baubles.

Advocacy

We have continued to play an active role in the appraisal of new treatments for porphyria, maintaining close collaboration with researchers and pharmaceutical companies to ensure that the patient perspective is integrated from the earliest stages of development. Our involvement helps to ensure that the real-life impact of porphyria on patients and families is considered throughout the research and regulatory process.

The BPA is also well represented on the international stage.

Dr Vicky McGuire (BPA Chair) was elected to the Ipnnet (International Porphyria Network) Executive Board as Treasurer from January 2025 (Ipnnet is a global clinician-led network). Vicky also plays an active role in the Ipnnet Porphyria Expert Clinical Centres (PECC) working group, which evaluates porphyria centres for recognition as expert centres. Liz Gill, Co-CEO, served as the patient representative on the Ipnnet Board until December 2024, stepping down after six years in the role. She remains a key contributor to IPNET's Acute Clinical Guidelines project, which is working to develop evidence-based international guidelines for the management of acute porphyria-an initiative that has the potential to significantly improve patient care worldwide, and is a member of the PECC working group alongside Dr Vicky McGuire.

The British Porphyria Association

Trustees' Annual Report *(continued)*

Year Ended 31 March 2025

Sue Burrell, Co-CEO, continues to hold a vital leadership role as President of the Global Porphyria Advocacy Coalition (GPAC). In this capacity, Sue works closely with patient organisations and pharmaceutical partners around the world to raise awareness of the porphyrias, develop educational resources for patients, and ensure that the BPA remains actively engaged in international collaborations and emerging drug development efforts.

Grant Making

It is the policy of the charity to give assistance to sufferers of porphyria to help towards their medical and physical requirements. We continue to support patients with additional needs due to their porphyria via a discretionary grant scheme. Funds are also made available to assist our members to attend our events where travel or accommodation costs would otherwise make it prohibitive for them to attend.

Monies in the Helen Gibbs Fund will continue to be allocated to acute porphyria patients who are eligible to receive the new treatment Givlaari, but who are unable to cover the cost of travelling to a porphyria centre to be able to receive this life changing treatment. These patients will need to visit a porphyria centre once a month for the first six months to receive the treatment and for ongoing monitoring and data collection. After the first six months, patients will receive their treatment at home. We expect there to be a handful of new patients each year that need this support for the first six months of treatment.

The British Porphyria Association

Trustees' Annual Report *(continued)*

Year Ended 31 March 2025

Financial Review

The BPA funds at 31 March 2025 consist of general funds of £47,420 and restricted funds totalling £19,907: £17,290 in the Helen Gibbs fund for research into acute porphyria, £1,385 in the Light Protection Fund reserved for grants to EPP patients and £1,232 in the Festival 2019 fund.

Our reserves policy is to hold sufficient funds to fund working capital and, as the charity is growing, to fund unexpected expenditure. These will include relevant meetings, for example the charity's involvement in the approval process of new drugs and attending meetings in the UK and overseas in the interests of the charity and our members. It will also include providing additional paid hours to fulfil other required obligations. As the charity's income is by way of subscriptions and donations the reserves will be used to cover any shortfalls in income or changes in circumstances.

Funding

BPA income derives from donations, fundraising and sponsored events, merchandise sales, grants, and sponsorship.

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.

We were greatly touched to receive a generous legacy donation in memory of Margaret Theresa Seary, who had AIP and had been a long-term supporter of the BPA.

We were the recipients of a National Lottery Community Fund grant which significantly contributed to the costs incurred in the 2024 Connect Alfresco event.

Our corporate supporters, Alnylam Pharmaceuticals, Disc Medicine, Mitsubishi Tanabe Pharma Company, Clinuvel UK, Alpket Foundation and Portal Therapeutics inc helped to support our patient events and attendance of key BPA personnel at other events. 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.

In July 2024, Clinuvel Ltd very generously donated over 400 bottles of CYACELLE Polychromatic Solar Protection large particle sun cream which we were able to send out to our skin porphyria community at a time when there were little other sunscreen protection options available. This was a huge help to our members and saw us reach many new patients via a social media campaign.

During the 2025-2026 financial year, we will be seeking funding to enable us to focus on, strengthen and protect our core organisational resilience as part of a development project.

The British Porphyria Association

Trustees' Annual Report *(continued)*

Year Ended 31 March 2025

Future Developments

In 2024, the BPA undertook a review and update of its two-year strategic plan. Building on our core principles of advocacy, support, education and research, and guided by the thematic pillars of Understand, Connect, Take Control and Share, we set out a number of key objectives for the coming year, in addition to the charity's ongoing operational activities:

- **Organisational resilience:** To strengthen the long-term sustainability of the BPA, we will begin work on updating internal systems and processes, investing in technology, and developing a succession planning framework to ensure continuity and operational effectiveness.
- **Research engagement:** We will support a range of studies and research projects, and maintain active collaboration with industry partners to encourage patient involvement and contribute to a more comprehensive understanding of the porphyria patient journey.
- **Mental health focus:** We will continue to prioritise the mental health and emotional wellbeing of individuals living with porphyria, recognising it as a critical component of holistic patient care.
- **Legacy video resources:** We aim to complete the editing of video content from the 2019 Festival event and the 2024 Connect Alfresco event. These resources will form part of a digital knowledge repository accessible to patients, families, healthcare professionals and the wider public, raising awareness and improving understanding of porphyria.
- **Peer support:** We will continue to offer online Peer Support Drop-in Sessions throughout 2025, providing regular opportunities for informal connection, mutual support and shared experience among community members.
- **Annual General Meeting:** Plans are in place to host the 2025 AGM as an in-person event, combined with a social and activity-based gathering in the Greater London area in Autumn 2025.

As always, we continue to encourage and support research into finding better treatments for all the porphyrias, and maintain and foster networks in the UK, Europe and globally.

Structure, Governance and Management

Governing document

The charity is governed by a constitution which is available from the trustees and represents an unincorporated charity.

Risk management

The trustees have a duty to identify and review the risks to which the charity is exposed and to ensure appropriate controls are in place to provide reasonable assurance against fraud and error.

Re-appointment of trustees

The trustees hold office for three years with no more than one third retiring at the annual general meeting. Subject to eligibility those retiring may be re-elected or re-appointed.

The British Porphyria Association

Trustees' Annual Report *(continued)*

Year Ended 31 March 2025

Reference and Administrative Details

Registered charity name	The British Porphyria Association
Charity registration number	1089609
Principal office	136 Devonshire Road Durham City County Durham DH1 2BL

The Trustees

A Newton
J W Chamberlayne (Chair until 30 September 2024)
K E Harris
A Molyneux
R Bennett (Secretary until 30 September 2024)
N Chadwick
V Harrold (Secretary from 30 September 2024)
V McGuire (Chair from 30 September 2024)
C Jarvis (Treasurer)

Independent Examiner	Jane Ascroft FCA MA (Cantab) Enterprise House Harmire Enterprise Park Barnard Castle County Durham DL12 8XT
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The trustees' annual report was approved on and signed on behalf of the board of trustees by:

V McGuire (Chair)
Trustee

The British Porphyria Association

Independent Examiner's Report to the Trustees of The British Porphyria Association

Year Ended 31 March 2025

I report to the trustees on my examination of the financial statements of The British Porphyria Association ('the charity') for the year ended 31 March 2025.

Responsibilities and Basis of Report

As the trustees of the charity you are responsible for the preparation of the financial statements in accordance with the requirements of the Charities Act 2011 ('the Act').

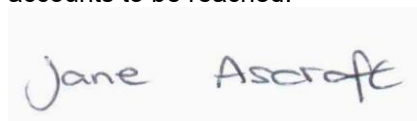
I report in respect of my examination of the charity's financial statements carried out under section 145 of the 2011 Act and in carrying out my examination I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

Independent Examiner's Statement

I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination giving me cause to believe that in any material respect:

1. accounting records were not kept in respect of the charity as required by section 130 of the Act; or
2. the financial statements do not accord with those records; or
3. the financial statements do not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a 'true and fair' view which is not a matter considered as part of an independent examination.

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.



Jane Ascroft FCA MA (Cantab)
Independent Examiner

Enterprise House
Harmire Enterprise Park
Barnard Castle
County Durham
DL12 8XT

The British Porphyria Association

Statement of Financial Activities

Year Ended 31 March 2025

			2025		2024
	Note	Unrestricted funds £	Restricted funds £	Total funds £	Total funds £
Income and endowments					
Donations	4	63,601	18,937	82,538	34,556
Other trading activities	5	689	–	689	81
Investment income	6	592	280	872	372
Other income	7	1,964	–	1,964	3,645
Total income		<u>66,846</u>	<u>19,217</u>	<u>86,063</u>	<u>38,654</u>
Expenditure					
Expenditure on raising funds:					
Costs of other trading activities	8	19	–	19	203
Expenditure on charitable activities	9,10	33,608	18,982	52,590	43,959
Total expenditure		<u>33,627</u>	<u>18,982</u>	<u>52,609</u>	<u>44,162</u>
Net income/(expenditure) and net movement in funds		<u>33,219</u>	<u>235</u>	<u>33,454</u>	<u>(5,508)</u>
Reconciliation of funds					
Total funds brought forward		14,201	19,672	33,873	39,381
Total funds carried forward		<u>47,420</u>	<u>19,907</u>	<u>67,327</u>	<u>33,873</u>

The statement of financial activities includes all gains and losses recognised in the year. All income and expenditure derive from continuing activities.

The notes on pages 11 to 17 form part of these financial statements.

The British Porphyria Association

Statement of Financial Position

31 March 2025

	Note	2025 £	2024 £
Current Assets			
Cash at bank and in hand		67,627	34,727
Creditors: amounts falling due within one year	15	<u>300</u>	<u>854</u>
Net Current Assets		<u>67,327</u>	<u>33,873</u>
Total Assets Less Current Liabilities		<u>67,327</u>	<u>33,873</u>
Net Assets		<u><u>67,327</u></u>	<u><u>33,873</u></u>
 Funds of the Charity			
Restricted funds		19,907	19,672
Unrestricted funds		<u>47,420</u>	<u>14,201</u>
Total charity funds	17	<u><u>67,327</u></u>	<u><u>33,873</u></u>

These financial statements were approved by the board of trustees and authorised for issue on, and are signed on behalf of the board by:

Claire Jarvis

C Jarvis (Treasurer)
Trustee

The notes on pages 11 to 17 form part of these financial statements.

The British Porphyria Association

Notes to the Financial Statements

Year Ended 31 March 2025

1. General Information

The charity is a public benefit entity and a registered charity in England and Wales and is unincorporated. The address of the principal office is 136 Devonshire Road, Durham City, County Durham, DH1 2BL.

2. Statement of Compliance

These financial statements have been prepared in compliance with FRS 102, 'The Financial Reporting Standard applicable in the UK and the Republic of Ireland', the Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (Charities SORP (FRS 102)) and the Charities Act 2011.

3. Accounting Policies

Basis of Preparation

The financial statements have been prepared on the historical cost basis, as modified by the revaluation of certain financial assets and liabilities and investment properties measured at fair value through income or expenditure.

The financial statements are prepared in sterling, which is the functional currency of the entity.

Going Concern

There are no material uncertainties about the charity's ability to continue.

Judgements and Key Sources of Estimation Uncertainty

The preparation of the financial statements requires management to make judgements, estimates and assumptions that affect the amounts reported. These estimates and judgements are continually reviewed and are based on experience and other factors, including expectations of future events that are believed to be reasonable under the circumstances. The Trustees consider that there are no significant estimates or judgements affecting these financial statements.

Fund Accounting

Unrestricted funds are available for use at the discretion of the trustees to further any of the charity's purposes.

Designated funds are unrestricted funds earmarked by the trustees for particular future project or commitment.

Restricted funds are subjected to restrictions on their expenditure declared by the donor or through the terms of an appeal, and fall into one of two sub-classes: restricted income funds or endowment funds.

The British Porphyria Association

Notes to the Financial Statements *(continued)*

Year Ended 31 March 2025

3. Accounting Policies *(continued)*

Income

All income is included in the statement of financial activities when entitlement has passed to the charity, it is probable that the economic benefits associated with the transaction will flow to the charity and the amount can be reliably measured. The following specific policies are applied to particular categories of income:

- income from donations or grants is recognised when there is evidence of entitlement to the gift, receipt is probable and its amount can be measured reliably.

Expenditure

Expenditure is recognised on an accruals basis as a liability is incurred. Expenditure includes any VAT which cannot be fully recovered, and is classified under headings of the statement of financial activities to which it relates:

- expenditure on charitable activities includes all costs incurred by a charity in undertaking activities that further its charitable aims for the benefit of its beneficiaries, including those support costs and costs relating to the governance of the charity apportioned to charitable activities.

All costs are allocated to expenditure categories reflecting the use of the resource. Direct costs attributable to a single activity are allocated directly to that activity. Shared costs are apportioned between the activities they contribute to on a reasonable, justifiable and consistent basis.

Financial Instruments

The charity only has financial assets and liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value and subsequently measured at their settlement value.

Debtors

Trade and other debtors are recognised at the settlement amount due after any trade discount offered. Prepayments are valued at the amount prepaid net of any trade discounts due.

Accrued income and tax recoverable is included at the best estimate of the amounts receivable at the balance sheet date.

Cash at Bank and in Hand

Cash at bank and cash in hand includes cash and short term highly liquid investments with a short maturity of three months or less from the date of acquisition or opening of the deposit or similar account.

The British Porphyria Association

Notes to the Financial Statements *(continued)*

Year Ended 31 March 2025

3. Accounting Policies *(continued)*

Creditors

Creditors are recognised where the charity has a present obligation resulting from a past event that will probably result in the transfer of funds to a third party and the amount due to settle the obligation can be measured or estimated reliably. Creditors are normally recognised at their settlement amount after allowing for any trade discounts due.

Taxation

The company is considered to pass the tests set out in Paragraph 1 Schedule 6 of the Finance Act 2010 and therefore it meets the definition of a charitable company for UK corporation tax purposes. Accordingly, the company is potentially exempt from taxation in respect of income or capital gains received within categories covered by Chapter 3 Part 11 of the Corporation Tax Act 2010 or Section 256 of the taxation of Chargeable Gains Act 1992, to the extent that such income or gains are applied exclusively to charitable purposes.

4. Donations

	Unrestricted Funds £	Restricted Funds £	Total Funds 2025 £
Donations			
Donations and subscriptions	20,613	1,377	21,990
Gift aid	4,125	–	4,125
Legacies			
Legacies	10,000	–	10,000
Grants			
Clinuvel Pharmaceuticals	2,000	–	2,000
Alnylam	6,555	–	6,555
Mitsubishi Tanab	10,000	–	10,000
National Lottery Community Fund	–	17,560	17,560
Portal Therapeutic	8,629	–	8,629
The Society for Inborn Errors of Metabolism (SSIEM)	1,679	–	1,679
	<u>63,601</u>	<u>18,937</u>	<u>82,538</u>

The British Porphyria Association

Notes to the Financial Statements (continued)

Year Ended 31 March 2025

4. Donations (continued)

	Unrestricted Funds £	Restricted Funds £	Total Funds 2024 £
Donations			
Donations and subscriptions	10,982	—	10,982
Gift aid	1,069	—	1,069
Other income	482	—	482
Grants			
Clinuvel Pharmaceuticals	2,000	—	2,000
Alnylam	10,000	—	10,000
Mitsubishi Tanab	—	—	—
Disc Medicine	9,523	—	9,523
Alpkit	—	500	500
	<u>34,056</u>	<u>500</u>	<u>34,556</u>

5. Other Trading Activities

	Unrestricted Funds £	Total Funds 2025 £	Unrestricted Funds £	Total Funds 2024 £
Merchandise sales	<u>689</u>	<u>689</u>	<u>81</u>	<u>81</u>

6. Investment Income

	Unrestricted Funds £	Restricted Funds £	Total Funds 2025 £
Bank interest receivable	592	280	872
Dividends receivable	—	—	—
	<u>592</u>	<u>280</u>	<u>872</u>
	Unrestricted Funds £	Restricted Funds £	Total Funds 2024 £
Bank interest receivable	132	228	360
Dividends receivable	12	—	12
	<u>144</u>	<u>228</u>	<u>372</u>

7. Other Income

	Unrestricted Funds £	Total Funds 2025 £	Unrestricted Funds £	Total Funds 2024 £
Consultancy fees	<u>1,964</u>	<u>1,964</u>	<u>3,645</u>	<u>3,645</u>

The British Porphyria Association

Notes to the Financial Statements *(continued)*

Year Ended 31 March 2025

8. Costs of Other Trading Activities

	Unrestricted Funds	Total Funds 2025	Unrestricted Funds	Total Funds 2024
	£	£	£	£
Merchandise costs	19	19	203	203

9. Expenditure on Charitable Activities by Fund Type

	Unrestricted Funds	Restricted Funds	Total Funds 2025
	£	£	£
Costs of charitable activities	33,608	18,982	52,590

	Unrestricted Funds	Restricted Funds	Total Funds 2024
	£	£	£
Costs of charitable activities	43,796	163	43,959

10. Expenditure on Charitable Activities by Activity Type

	Activities undertaken directly	Grant funding of activities	Total funds 2025	Total fund 2024
	£	£	£	£
Costs of charitable activities	52,500	90	52,590	43,959

11. Analysis of Grants

	2025 £	2024 £
Grants to Individuals		
Travel bursaries	—	50
Other grants	90	113
Total grants	90	163

12. Independent Examination Fees

	2025 £	2024 £
Fees payable to the independent examiner for: Independent examination of the financial statements	300	300

13. Staff Costs

The average head count of employees during the year was Nil (2024: Nil).

The British Porphyria Association

Notes to the Financial Statements *(continued)*

Year Ended 31 March 2025

13. Staff Costs *(continued)*

No employee received employee benefits of more than £60,000 during the year (2024: Nil).

14. Trustee Remuneration and Expenses

There were no trustees' remuneration or other benefits for the current or previous year.

During the year travel expenses of £1,669 were reimbursed to 8 trustees (2024 - £1,046 to 4 trustees).

15. Creditors: amounts falling due within one year

	2025	2024
	£	£
Accruals and deferred income	300	854

16. Deferred Income

	2025	2024
	£	£
At 1 April 2024	554	—
Amount released to income	(554)	—
Amount deferred in year	—	554
At 31 March 2025	—	554

17. Analysis of Charitable Funds

Unrestricted funds

	At 1 April 2024	Income	Expenditure	At 31 March 2025
	£	£	£	£
General funds	14,201	66,846	(33,627)	47,420

	At 1 April 2023	Income	Expenditure	At 31 March 2024
	£	£	£	£
General funds	20,274	37,926	(43,999)	14,201

The British Porphyria Association

Notes to the Financial Statements (continued)

Year Ended 31 March 2025

17. Analysis of Charitable Funds (continued)

Restricted funds

	At 1 April 2024 £	Income £	Expenditure £	At 31 March 2025 £
Helen Gibbs Fund	17,038	252	–	17,290
Light Protection Fund	920	1,387	(922)	1,385
Festival 2019 fund	1,214	18	–	1,232
National Lottery Community Fund	–	17,560	(17,560)	–
Alpkit	500	–	(500)	–
	<u>19,672</u>	<u>19,217</u>	<u>(18,982)</u>	<u>19,907</u>

	At 1 April 2023 £	Income £	Expenditure £	At 31 March 2024 £
Helen Gibbs Fund	16,885	203	(50)	17,038
Light Protection Fund	1,022	11	(113)	920
Festival 2019 fund	1,200	14	–	1,214
Alpkit	–	500	–	500
	<u>19,107</u>	<u>728</u>	<u>(163)</u>	<u>19,672</u>

The Helen Gibbs fund is for research into acute porphyria and the Light Protection Fund is reserved for grants to EPP patients.

The Festival 2019 fund includes a grant from Orphan Europe to help towards our Porphyria Festival in October 2019 to celebrate our 20th anniversary.

18. Analysis of Net Assets Between Funds

	Unrestricted Funds £	Restricted Funds £	Total Funds 2025 £
Current assets	47,720	19,907	67,627
Creditors less than 1 year	(300)	–	(300)
Net assets	<u>47,420</u>	<u>19,907</u>	<u>67,327</u>

	Unrestricted Funds £	Restricted Funds £	Total Funds 2024 £
Current assets	15,055	19,672	34,727
Creditors less than 1 year	(854)	–	(854)
Net assets	<u>14,201</u>	<u>19,672</u>	<u>33,873</u>

The British Porphyria Association

Management Information

Year Ended 31 March 2025

The Following Pages Do Not Form Part of the Financial Statements.

The British Porphyria Association

Detailed Statement of Financial Activities

Year Ended 31 March 2025

	2025 £	2024 £
Income and endowments		
Donations		
Donations and subscriptions	21,990	10,982
Gift aid	4,125	1,069
Other income	—	482
Legacies	10,000	—
Clinuvel Pharmaceuticals	2,000	2,000
Alnylam	6,555	10,000
Mitsubishi Tanab	10,000	—
Disc Medicine	—	9,523
National Lottery Community Fund	17,560	—
Alpkit	—	500
Portal Therapeutic	8,629	—
The Society for Inborn Errors of Metabolism (SSIEM)	1,679	—
	<u>82,538</u>	<u>34,556</u>
Other trading activities		
Merchandise sales	<u>689</u>	<u>81</u>
Investment income		
Bank interest receivable	872	360
Dividends receivable	<u>—</u>	<u>12</u>
	<u>872</u>	<u>372</u>
Other income		
Consultancy fees	<u>1,964</u>	<u>3,645</u>
Total income	<u>86,063</u>	<u>38,654</u>

The British Porphyria Association

Detailed Statement of Financial Activities *(continued)*

Year Ended 31 March 2025

	2025 £	2024 £
Expenditure		
Costs of other trading activities		
Merchandise costs	19	203
Expenditure on charitable activities		
BPA events	341	10,608
Alfresco Event	10,249	—
BIPNET collaboration event	—	2,600
Insurance	1,196	1,141
Trustees' ordinary travel expenses	1,669	1,046
Ordinary travel expenses	3,694	3,150
Accountancy fees	300	264
Storage fees	625	589
Printing, postage, stationery and telephone	3,889	1,726
Newsletter	388	665
Advertising and promotional goods	828	—
Subscriptions	338	389
IT and software	1,835	523
Fundraising	913	775
Sundry costs	219	188
Administration fees	23,776	20,132
Outsourced Work	2,240	—
	52,500	43,796
Grant funding activities		
Grants given	90	163
Expenditure on charitable activities	52,590	43,959
Total expenditure	52,609	44,162
Net income/(expenditure)	33,454	(5,508)