

THE BRITISH PORPHYRIA ASSOCIATION

England & Wales - Charity number 1089609

Details

Status Registered

Legal form Other

Registered 2001-11-30

Register [View on the Charity Commission register](#)

Contact

Address 4 Festival Villas
Woodland
Bishop Auckland
County Durham
DL13 5RG

Phone 0300 30 200 30

Email helpline@porphyria.org.uk

Website www.porphyria.org.uk

Activities

Objects: 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: Support for people with porphyria and their relatives. Improve understanding of porphyria. Support research into porphyria.

Classification

- **How:** Makes Grants To Individuals, Provides Advocacy/advice/information, Sponsors Or Undertakes Research, Acts As An Umbrella Or Resource Body
- **What:** Education/training, The Advancement Of Health Or Saving Of Lives
- **Who:** Other Defined Groups

Geography

- Northern Ireland
- Scotland
- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2025-03-31	£86,063	£52,609	-	-
2024-03-31	£38,654	£44,162	-	-
2023-03-31	£43,549	£48,132	-	-
2022-03-31	£23,062	£23,111	-	-
2021-03-31	£25,650	£22,597	-	-

Trustees

Name	Role	Appointed
Dr Victoria Anne McGuire	Chair	2024-09-30
ALAN MOLYNEUX		
ANNE NEWTON		2001-11-30
Claire Jarvis		2024-03-19
JOHN WALTER CHAMBERLAYNE MA		2024-09-30
KAREN ELIZABETH HARRIS		2001-11-30
Natassja Chadwick		2020-09-19
Richard Bennett		2018-04-19
Victoria Harrold		2023-10-03

THE BRITISH PORPHYRIA ASSOCIATION

England & Wales - Charity number 1089609

Accounts

Charity Registration Number: 1089609

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 Alpkit 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, Alynham Pharmaceuticals, Disc Medicine, Mitsubishi Tanabe Pharma Company, Clinuvel UK, Alpkit 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

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').

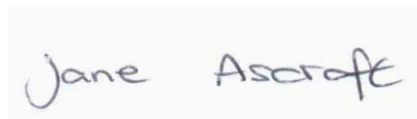
I report in respect of my examination of the charity's financial statements carried out under section 145 of the 2011 Act and in carrying out my examination I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

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

		Unrestricted funds	2025 Restricted funds	Total funds	2024 Total funds
	Note	£	£	£	£
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	–	12
	<u>872</u>	<u>372</u>
Other income		
Consultancy fees	<u>1,964</u>	<u>3,645</u>
Total income	<u><u>86,063</u></u>	<u><u>38,654</u></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	–
	<u>52,500</u>	<u>43,796</u>
Grant funding activities		
Grants given	90	163
	<u>52,590</u>	<u>43,959</u>
Expenditure on charitable activities		
	<u>52,590</u>	<u>43,959</u>
Total expenditure	<u>52,609</u>	<u>44,162</u>
Net income/(expenditure)	<u>33,454</u>	<u>(5,508)</u>

THE BRITISH PORPHYRIA ASSOCIATION

England & Wales - Charity number 1089609

Accounts

Charity Registration Number: 1089609

The British Porphyria Association
Financial Statements
For the Year Ending
31 March 2024

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 2024

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The British Porphyria Association

Trustees' Annual Report

Year Ended 31 March 2024

The trustees present their report and the unaudited financial statements of the charity for the year ended 31 March 2024.

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 2023-2024 financial year has again been very busy for the BPA. We continued to work towards our aims to advocate for, support and educate porphyria patients, as well as relatives and medical professionals, so as 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

Commencing on 19 April 2023, Global Porphyria Day (GPD), previously known as Porphyria Awareness Week, provided the opportunity to raise awareness about porphyria as well as opportunities for patients and their families and friends to get involved in the theme of This Is My Porphyria. The day produced great engagement across many countries.

The British Porphyria Association

Trustees' Annual Report *(continued)*

Year Ended 31 March 2024

CONFERENCES AND EVENTS

In June 2023, we were pleased to hold a face-to-face patient conference at the SnowDome Conference Facility in Tamworth. The event began with a quiz and social evening on the Saturday giving families the opportunity to connect informally. The feedback was overwhelmingly positive and enjoyed by all in attendance. The Sunday brought together some excellent patient stories followed by research updates and Q&A sessions with UK porphyria experts.

A handful of the BPA team presented and took part in the BIPNET (British & Irish Porphyria Network – a clinician-led best practice network) Annual Conference the following day. The joint collaboration between BIPNET and the BPA is a great opportunity for reciprocal knowledge sharing and education.

We had planned a two-day residential event in September 2023 however, due to unforeseen circumstances, the event was postponed until October 2024.

Our AGM was held virtually in October 2023, so we took the opportunity to hold an online social gathering where people could connect with others with their type of porphyria, and gain more input from our community on what young people would value on the postponed residential activity. During the AGM two attendees volunteered their services as trustees, Dr Vicky McGuire, who is also a BPA patron and Victoria Harold, one of our committee members. They were both duly appointed trustees on 29 November 2023.

We returned to Dublin on Sunday 3 March 2024 for a much-needed Patient Day in Ireland. The event was organised with the support of St James's Hospital, Dublin and the BIPNET team. The programme included doctor and patient talks, research updates from pharmaceutical companies, and Q&A sessions, and was attended by patients, their families and friends, and medical professionals. The patient day was again followed by the BIPNET Annual Conference, where the BPA took an active role in collaborating with medical professionals and lab staff to enhance the porphyria knowledge base.

In March 2024, we also held our first online Peer Support Group Drop-In Session to support patients with EPP/XLP and other skin porphyrias. The session was open to all ages, and families affected were encouraged to attend together. This is a new 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.

BPA TEAM

We were delighted that in March 2024, Claire Jarvis, who had been volunteering for the BPA during the financial year, agreed to become our new Treasurer and a Trustee. Claire was appointed a trustee on 19 March 2024.

WEBSITE, SOCIAL MEDIA & HELPLINES

With the continuing support of the BPA's paid administrator, the BPA have made great strides this year in engaging a larger audience on social media, where content interaction saw a 56% increase on the prior year and our reach increased by 20%. Our net followers increased by 97 (an increase of 53%) in the 2023-2024 year.

Twice yearly newsletters were produced and sent out to our members and merchandise was purchased for fundraising and awareness. BPA funds were used for administration fees, printing and postage. A Christmas fundraising campaign was held again in 2023, selling Christmas cards and baubles.

ADVOCACY We continued to take an active part in appraisals of new treatments for porphyria and maintain our involvement with researchers and companies exploring potential treatments to ensure the

The British Porphyria Association

Trustees' Annual Report *(continued)*

Year Ended 31 March 2024

patient voice is considered at the early stages of research, and that the impact of the condition on patients is considered throughout the process.

The BPA has been well-represented internationally through Liz Gill's role as the patient representative on the Executive Board of Ipnet (International Porphyria Network – a global clinician-led network). As well as being one of the BPA's strategic leads, Liz is also heavily involved in the Ipnet Acute Clinical Guidelines project, which aims to develop evidence-based guidelines for the care of acute porphyria patients around the world.

Holding an instrumental role, Sue Burrell is the Global Porphyria Advocacy Coalition (GPAC) President, as well as one of the BPA's strategic leads. She works with other patient organisations and pharmaceutical companies to raise awareness of the porphyrias and develop resources for patients, as well as ensuring that the BPA is at the forefront of collaborations with new drug development research.

Grant Making

It is the policy of the charity to give assistance to sufferers of porphyria to help towards their medical and physical requirements. Funds are made available to assist our members to attend our events with £50 towards travel and £50 towards an overnight stay.

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 2024

Financial Review

The BPA funds at 31 March 2024 consist of general funds of £15,557 and restricted funds totalling £19,171: £17,038 in the Helen Gibbs fund for research into acute porphyria, £920 in the Light Protection Fund reserved for grants to EPP patients and £1,213 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.

Our corporate supporters, Alynham 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.

During the 2024-2025 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 2024

Future Developments

In 2024 we are updating our two-year strategic plan. In addition to the day-to-day running of the charity and to fulfil our overarching advocacy principles of support, education and research, through our themes of Understand, Connect, Take Control and Share, some of the things we would like to achieve in the coming year are:

- Continue to provide a focus on the mental health of people living with porphyria.
- Host a two-day Residential Event in October at Thorpe Woodlands Adventure Centre, Thetford Forest. The event is designed to offer a safe residential environment with numerous outdoor activities for children and young people affected by Erythropoietic protoporphyria (EPP). We will also be arranging for family members to meet with other parents/siblings to build our EPP support community further.
- We plan to send representatives to the International Congress on Porphyrins and Porphyria (ICPP) in Pamplona, Spain on 21-25 September 2024. As always, we will be actively engaged (alongside clinicians, researchers, scholars, patients and their families) over a number of days to build further connections and learn about the latest research and developments in the field of porphyria.
- Develop our resilience as an organisation by making plans to update technology and processes, as well as consider succession planning to ensure that we remain strong as an organisation and able to deliver vital services.
- Continue with legacy video-editing work from the Festival in 2019 and Reconnect Dundee in 2022 to make presentations available to enhance knowledge and understanding of porphyria. These are available online to patients, relatives and medical professionals working with porphyria patients.
- Facilitate further online Peer Support Drop-in Sessions during 2024.
- Hold our AGM virtually in Autumn 2024 followed by a social event.

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 2024

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 (Treasurer)
J W Chamberlayne
K E Harris
A Molyneux
R Bennett
N Chadwick
V Harrold
V McGuire
C Jarvis

Independent Examiner Jane Ascroft FCA MA (Cantab)
 Enterprise House
 Harmire Enterprise Park
 Barnard Castle
 County Durham
 DL12 8XT

The trustees' annual report was approved on12 June 2024 and signed on behalf of the board of trustees by:



J W Chamberlayne
Trustee

The British Porphyria Association

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

Year Ended 31 March 2024

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 2024.

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').

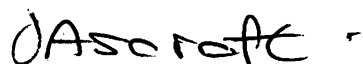
I report in respect of my examination of the charity's financial statements carried out under section 145 of the 2011 Act and in carrying out my examination I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

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 2024

		2024	2023		
	Note	Unrestricted funds £	Restricted funds £	Total funds £	Total funds £
Income and endowments					
Donations	4	34,056	500	34,556	40,722
Other trading activities	5	81	–	81	508
Investment income	6	144	228	372	96
Other income	7	3,645	–	3,645	2,223
Total income		<u>37,926</u>	<u>728</u>	<u>38,654</u>	<u>43,549</u>
Expenditure					
Expenditure on raising funds:					
Costs of other trading activities	8	203	–	203	345
Expenditure on charitable activities	9,10	43,796	163	43,959	47,787
Total expenditure		<u>43,999</u>	<u>163</u>	<u>44,162</u>	<u>48,132</u>
Net expenditure and net movement in funds					
		<u>(6,073)</u>	<u>565</u>	<u>(5,508)</u>	<u>(4,583)</u>
Reconciliation of funds					
Total funds brought forward		<u>20,274</u>	<u>19,107</u>	<u>39,381</u>	<u>43,964</u>
Total funds carried forward		<u>14,201</u>	<u>19,672</u>	<u>33,873</u>	<u>39,381</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 10 to 16 form part of these financial statements.

The British Porphyria Association

Statement of Financial Position

31 March 2024

	Note	2024 £	2023 £
Current Assets			
Debtors	15	–	108
Cash at bank and in hand		34,727	39,573
		<u>34,727</u>	<u>39,681</u>
Creditors: amounts falling due within one year	16	854	300
Net Current Assets		<u>33,873</u>	<u>39,381</u>
Total Assets Less Current Liabilities		<u>33,873</u>	<u>39,381</u>
Net Assets		<u>33,873</u>	<u>39,381</u>
Funds of the Charity			
Restricted funds		19,672	19,107
Unrestricted funds		14,201	20,274
Total charity funds	18	<u>33,873</u>	<u>39,381</u>

These financial statements were approved by the board of trustees and authorised for issue on 12 June 2024 and are signed on behalf of the board by:



A Newton (Treasurer)
Trustee

The notes on pages 10 to 16 form part of these financial statements.

The British Porphyria Association

Notes to the Financial Statements

Year Ended 31 March 2024

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 2024

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 2024

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 2024 £
Donations			
Donations and subscriptions	10,982	–	10,982
Gift aid	1,069	–	1,069
Other income	482	–	482
Grants			
Clinuvel Pharmaceuticals grant	2,000	–	2,000
Alnylam grant	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>
	Unrestricted Funds £	Restricted Funds £	Total Funds 2023 £
Donations			
Donations and subscriptions	16,438	–	16,438
Gift aid	1,400	–	1,400
Other income	–	–	–

The British Porphyria Association

Notes to the Financial Statements (continued)

Year Ended 31 March 2024

4. Donations (continued)

	Unrestricted Funds £	Restricted Funds £	Total Funds 2023 £
Grants			
Clinuvel Pharmaceuticals grant	–	–	–
Anylam grant	10,000	–	10,000
Mitsubishi Tanab	2,500	–	2,500
Disc Medicine	–	884	884
National Lottery Community Fund	–	9,500	9,500
	<u>30,338</u>	<u>10,384</u>	<u>40,722</u>

5. Other Trading Activities

	Unrestricted Funds £	Total Funds 2024 £	Unrestricted Funds £	Total Funds 2023 £
Merchandise sales	<u>81</u>	<u>81</u>	<u>508</u>	<u>508</u>

6. Investment Income

	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>

	Unrestricted Funds £	Restricted Funds £	Total Funds 2023 £
Bank interest receivable	40	42	82
Dividends receivable	14	–	14
	<u>54</u>	<u>42</u>	<u>96</u>

7. Other Income

	Unrestricted Funds £	Total Funds 2024 £	Unrestricted Funds £	Total Funds 2023 £
Consultancy fees	<u>3,645</u>	<u>3,645</u>	<u>2,223</u>	<u>2,223</u>

The British Porphyria Association

Notes to the Financial Statements (continued)

Year Ended 31 March 2024

8. Costs of Other Trading Activities

	Unrestricted Funds £	Total Funds 2024 £	Unrestricted Funds £	Total Funds 2023 £
Merchandise costs	<u>203</u>	<u>203</u>	<u>345</u>	<u>345</u>

9. Expenditure on Charitable Activities by Fund Type

	Unrestricted Funds £	Restricted Funds £	Total Funds 2024 £
Costs of charitable activities	<u>43,796</u>	<u>163</u>	<u>43,959</u>

	Unrestricted Funds £	Restricted Funds £	Total Funds 2023 £
Costs of charitable activities	<u>37,054</u>	<u>10,733</u>	<u>47,787</u>

10. Expenditure on Charitable Activities by Activity Type

	Activities undertaken directly £	Grant funding of activities £	Total funds 2024 £	Total fund 2023 £
Costs of charitable activities	<u>43,796</u>	<u>163</u>	<u>43,959</u>	<u>47,787</u>

11. Analysis of Grants

	2024 £	2023 £
Grants to Individuals		
Travel bursaries	50	349
Other grants	<u>113</u>	<u>300</u>
	<u>163</u>	<u>649</u>
Total grants	<u>163</u>	<u>649</u>

12. Independent Examination Fees

	2024 £	2023 £
Fees payable to the independent examiner for: Independent examination of the financial statements	<u>300</u>	<u>300</u>

13. Staff Costs

The average head count of employees during the year was Nil (2023: Nil).

The British Porphyria Association

Notes to the Financial Statements (continued)

Year Ended 31 March 2024

13. Staff Costs (continued)

No employee received employee benefits of more than £60,000 during the year (2023: Nil).

14. Trustee Remuneration and Expenses

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

During the year expenses of £1,046 were reimbursed to 4 trustees (2023 - £2,682 to 5 trustees).

15. Debtors

	2024	2023
	£	£
Gift aid receivable	<u>–</u>	<u>108</u>

16. Creditors: amounts falling due within one year

	2024	2023
	£	£
Accruals and deferred income	<u>854</u>	<u>300</u>

17. Deferred Income

	2024	2023
	£	£
Amount deferred in year	<u>554</u>	<u>–</u>

18. Analysis of Charitable Funds

Unrestricted funds

	At 1 April 2023	Income	Expenditure	Transfers	At 31 March 2024
	£	£	£	£	£
General funds	<u>20,274</u>	<u>37,926</u>	<u>(43,999)</u>	<u>–</u>	<u>14,201</u>

	At 1 April 2022	Income	Expenditure	Transfers	At 31 March 2023
	£	£	£	£	£
General funds	<u>24,545</u>	<u>33,123</u>	<u>(37,399)</u>	<u>5</u>	<u>20,274</u>

The British Porphyria Association

Notes to the Financial Statements *(continued)*

Year Ended 31 March 2024

18. Analysis of Charitable Funds *(continued)*

Restricted funds

	At 1 April 2023	Income	Expenditure	Transfers	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>–</u>	<u>19,672</u>

	At 1 April 2022	Income	Expenditure	Transfers	At 31 March 2023
	£	£	£	£	£
Helen Gibbs Fund	17,197	37	(349)	–	16,885
Light Protection Fund	1,025	2	–	(5)	1,022
Festival 2019 fund	1,197	3	–	–	1,200
National Lottery Community Fund	–	9,500	(9,500)	–	–
Disc Medicine	–	884	(884)	–	–
	<u>19,419</u>	<u>10,426</u>	<u>(10,733)</u>	<u>(5)</u>	<u>19,107</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.

19. Analysis of Net Assets Between Funds

	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>

	Unrestricted Funds £	Restricted Funds £	Total Funds 2023 £
Current assets	21,458	18,223	39,681
Creditors less than 1 year	(300)	–	(300)
Net assets	<u>21,158</u>	<u>18,223</u>	<u>39,381</u>

The British Porphyria Association

Management Information

Year Ended 31 March 2024

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

The British Porphyria Association

Detailed Statement of Financial Activities

Year Ended 31 March 2024

	2024 £	2023 £
Income and endowments		
Donations		
Donations and subscriptions	10,982	16,438
Gift aid	1,069	1,400
Other income	482	–
Clinuvel Pharmaceuticals grant	2,000	–
Alnylam grant	10,000	10,000
Mitsubishi Tanab	–	2,500
Disc Medicine	9,523	884
National Lottery Community Fund	–	9,500
Alpkit	500	–
	<u>34,556</u>	<u>40,722</u>
Other trading activities		
Merchandise sales	<u>81</u>	<u>508</u>
Investment income		
Bank interest receivable	360	82
Dividends receivable	12	14
	<u>372</u>	<u>96</u>
Other income		
Consultancy fees	<u>3,645</u>	<u>2,223</u>
Total income	<u>38,654</u>	<u>43,549</u>

The British Porphyria Association

Detailed Statement of Financial Activities *(continued)*

Year Ended 31 March 2024

	2024 £	2023 £
Expenditure		
Costs of other trading activities		
Merchandise costs	<u>203</u>	<u>345</u>
Expenditure on charitable activities		
<i>Activities undertaken directly</i>		
BPA events	10,608	10,935
Counselling & wellbeing	–	230
BIPNET collaboration event	2,600	–
Insurance	1,141	1,068
International conference fees	–	1,231
Trustees' ordinary travel expenses	1,046	2,682
Ordinary travel expenses	3,150	4,152
Accountancy fees	264	300
Storage fees	589	584
Printing, postage, stationery and telephone	1,726	1,244
Newsletter	665	550
Advertising and promotional goods	–	586
Subscriptions	389	346
IT and software	523	519
Fundraising	775	684
Sundry costs	188	–
Administration fees	20,132	19,804
Administration fees - Festival	–	2,223
	<u>43,796</u>	<u>47,138</u>
<i>Grant funding activities</i>		
Grants given	<u>163</u>	<u>649</u>
	<u>43,959</u>	<u>47,787</u>
Expenditure on charitable activities	<u>43,959</u>	<u>47,787</u>
Total expenditure	<u>44,162</u>	<u>48,132</u>
Net expenditure	<u>(5,508)</u>	<u>(4,583)</u>

THE BRITISH PORPHYRIA ASSOCIATION

England & Wales - Charity number 1089609

Accounts

Charity Registration Number: 1089609

The British Porphyria Association
Financial Statements
For the Year Ending
31 March 2023

JANE ASCROFT ACCOUNTANCY LIMITED

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

The British Porphyria Association

Financial Statements

Year Ended 31 March 2023

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The British Porphyria Association

Trustees' Annual Report

Year Ended 31 March 2023

The trustees present their report and the unaudited financial statements of the charity for the year ended 31 March 2023.

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 BPA commenced the financial year by taking part in International Porphyria Awareness Week on social media in April 2022 which produced great engagement across many countries.

The 2022-2023 financial year has been very busy with meetings and events.

Starting In May 2022 we were pleased to hold our first face to face event since Covid 19. BPA Re-Connect was held in Dundee with over 40 people attending in person. We also live-streamed some of the sessions which will be uploaded to our YouTube channel in due course. The event included acute and skin Q&A panel discussions, a patient story and sessions on the importance of physical and mental health. 100% positive feedback was received for all the sessions.

Representatives from the BPA attended the International Congress on Porphyrins and Porphyrias (ICPP) in September 2022 in Sofia, Bulgaria and also the ICPP Patient Day which preceded the main Congress. The two strategic leads were also heavily involved in global patient advocacy movements: Sue via the Global Porphyria Advocacy Coalition (GPAC) and Liz as the patient representative for the international patient groups on the European Porphyria Network (Epnet).

The congress brought together the whole porphyria community of patients, patient advocates, scientists, treating physicians, researchers and pharmaceutical partners who came together to focus on porphyria. There were scientific talks and presentations, updates on current therapies and treatments as well as updates on new and emerging therapies.

An award of £9,500 from The National Lottery Community Fund enabled us to hold BPA Connect Alfresco at Temple Newsome in Leeds in October 2022. This event brought together 55 individuals including 13 families with at least one member affected by EPP. The day commenced with our AGM and a Lego workshop followed by a tree-top adventure at Go Ape. The afternoon's team activities included a treasure hunt and an orienteering activity. The day was a huge success with attendees suggesting that it should be longer, confirming our hopes that a two-day or residential event in 2023 is worth exploring. Disc Medicine also helped to sponsor this event with their funds enabling us to bring two families from Ireland to attend the event.

During the financial year ending 31 March 2023, funds were used for administration fees, printing, postage, insurance and membership fees to relevant organisations. Twice yearly newsletters were produced and sent out to our members and merchandise was purchased for fundraising and awareness.

The British Porphyria Association

Trustees' Annual Report *(continued)*

Year Ended 31 March 2023

We held a Christmas fundraising campaign again in 2022, selling Christmas cards and baubles.

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

Danil Lopukhov, our new treasurer and trustee, resigned due to work commitments with immediate effect in January 2023. Anne Newton temporarily took on the responsibility as Acting Treasurer while a new Treasurer is found. We wish Danil well in the future.

At the end of the 2022-2023 financial year the BPA appointed a new administrative assistant, Georgia Newman to assist with some of the general administration of the charity, working 20 hours a month. We also welcomed a new volunteer, Claire Jarvis. These new appointments will help us to move the charity forward with our future plans and developments.

We are actively looking to appoint a new Treasurer/Trustee to oversee the BPA's financial administrative responsibilities.

The BPA are delighted to announce that Dr Vicky McGulre, the Principal Clinical Scientist working at the Scottish Cutaneous Porphyria Service in Dundee has become a BPA patron. Vicky is also the joint-Chair of the British and Irish Porphyria Network (BIPNET). Vicky became actively involved in the BPA in 2019 at our Festival Event in Manchester where she brought a really fresh slant to the science behind porphyria. Vicky has, since then, been an active member of our volunteer team. We are very grateful for the support and time Vicky has already dedicated to the BPA and we look forward to future collaborations and support in the years to come.

Grantmaking

It is the policy of the charity to give assistance to sufferers of porphyria to help towards their medical and physical requirements. Funds are made available to assist our members to attend our events with £50 towards travel and £50 towards an overnight stay.

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 2023

Financial Review

The BPA funds at 31 March 2023 consist of general funds of £20,274 and restricted funds totalling £19,107: £16,885 in the Helen Gibbs fund for research into acute porphyria, £1,022 in the Light Protection Fund reserved for grants to EPP patients and £1,200 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, particularly during this last difficult year. We really couldn't continue to do the work that we are doing without these amazing efforts.

Our supporters, the National Lottery Community Fund, Alnylam Pharmaceuticals, Recordati Rare Diseases, Mitsubishi Tanabe, Clinuvel Pharmaceuticals and Disc Medicine have helped to support programme of work over the year and beyond. 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.

Recently, some of our charity leaders also took part in projects that required them to provide their expert porphyria knowledge and input to research studies in an advisory capacity, for which the BPA will be recompensed for their time during the 2023-24 financial year.

During the 2023-24 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 2023

Future Developments

In early 2023 we updated our two-year strategic plan. Our overarching advocacy principles of support, education and research continue through our themes of Understand, Connect, Take Control and Share. Some of the things we would like to achieve in the coming year are:

- Continue to provide a focus on the mental health of people living with porphyria.
- Host a two-day Patient Event in June (in conjunction with the British & Irish Porphyria Network) at the SnowDome Conference Facility Tamworth (with a Social Evening on Day 1 and a Patient Day on Day 2, which will include doctor and patient talks, updates on research and plenty of opportunities for patients to speak to each other.
- Facilitate a two-day residential, BPA Connect Alfresco, in September 2023 which will take place in a forest venue near Thetford, Norfolk. The event is being designed primarily to be a safe activity for children and young people affected by erythropoietic protoporphyria (EPP), but all will be welcome to get involved in an active challenge or two!
- Develop our resilience as an organisation by making plans to update technology and processes, as well as consider succession planning to ensure that we remain strong as an organisation and able to deliver vital services.
- Continue with legacy video-editing work from the Festival in 2019 and Reconnect Dundee in 2022 to make presentations available to enhance knowledge and understanding of porphyria. These are available online to patients, relatives and medical professionals working with porphyria patients.

As always, we continue with the day to day running of the charity, and encourage and support research into finding better treatments for all the porphyrias. We also 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 2023

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 (Treasurer)
J W Chamberlayne
K E Harris
A Molyneux
R Bennett
N Chadwick

Danil Lopukhov

(Served from 15 October 2022 to
23 February 2023)

Independent Examiner Jane Ascroft FCA MA (Cantab)
Enterprise House
Harmire Enterprise Park
Barnard Castle
County Durham
DL12 8XP

The trustees' annual report was approved on 11/7/23 and signed on behalf of the board of trustees by:



J W Chamberlayne
Trustee

The British Porphyria Association

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

Year Ended 31 March 2023

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 2023.

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 8XP

The British Porphyria Association

Statement of Financial Activities

Year Ended 31 March 2023

		2023	2022		
	Note	Unrestricted funds £	Restricted funds £	Total funds £	Total funds £
Income and endowments					
Donations	4	30,338	10,384	40,722	22,147
Other trading activities	5	508	–	508	906
Investment income	6	54	42	96	9
Other income	7	2,223	–	2,223	–
Total income		<u>33,123</u>	<u>10,426</u>	<u>43,549</u>	<u>23,062</u>
Expenditure					
Expenditure on raising funds:					
Costs of other trading activities	8	345	–	345	1,468
Expenditure on charitable activities	9,10	37,054	10,733	47,787	21,643
Total expenditure		<u>37,399</u>	<u>10,733</u>	<u>48,132</u>	<u>23,111</u>
Net expenditure		<u>(4,276)</u>	<u>(307)</u>	<u>(4,583)</u>	<u>(49)</u>
Transfers between funds		5	(5)	–	–
Net movement in funds		<u>(4,271)</u>	<u>(312)</u>	<u>(4,583)</u>	<u>(49)</u>
Reconciliation of funds					
Total funds brought forward		24,545	19,419	43,964	44,013
Total funds carried forward		<u>20,274</u>	<u>19,107</u>	<u>39,381</u>	<u>43,964</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 9 to 15 form part of these financial statements.


The British Porphyria Association

Statement of Financial Position

31 March 2023

	Note	2023 £	2022 £
Current Assets			
Debtors	15	108	117
Cash at bank and in hand		39,573	44,099
		<u>39,681</u>	<u>44,216</u>
Creditors: amounts falling due within one year	16	<u>300</u>	<u>252</u>
Net Current Assets		<u>39,381</u>	<u>43,964</u>
Total Assets Less Current Liabilities		<u>39,381</u>	<u>43,964</u>
Net Assets		<u>39,381</u>	<u>43,964</u>
Funds of the Charity			
Restricted funds		19,107	19,419
Unrestricted funds		20,274	24,545
Total charity funds	17	<u>39,381</u>	<u>43,964</u>

These financial statements were approved by the board of trustees and authorised for issue on ..11/7/23.., and are signed on behalf of the board by:



A Newton (Treasurer)
Trustee

The notes on pages 9 to 15 form part of these financial statements.

The British Porphyria Association

Notes to the Financial Statements

Year Ended 31 March 2023

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 2023

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 2023

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 2023 £
Donations			
Donations and subscriptions	16,438	–	16,438
Gift aid	1,400	–	1,400
Grants			
Alylam grant	10,000	–	10,000
Mitsubishi Tanab	2,500	–	2,500
Disc Medicine	–	884	884
National Lottery Community Fund	–	9,500	9,500
	<u>30,338</u>	<u>10,384</u>	<u>40,722</u>
	Unrestricted Funds £	Restricted Funds £	Total Funds 2022 £
Donations			
Donations and subscriptions	10,019	–	10,019
Gift aid	1,128	–	1,128

The British Porphyria Association

Notes to the Financial Statements (continued)

Year Ended 31 March 2023

4. Donations (continued)

	Unrestricted Funds £	Restricted Funds £	Total Funds 2022 £
Grants			
Clinuvel Pharmaceuticals grant	1,000	–	1,000
Alnylam grant	2,000	–	2,000
Recordati Rare Diseases grant	5,000	–	5,000
Albert Hunt	1,000	–	1,000
Mitsubishi Tanab	2,000	–	2,000
	<u>22,147</u>	<u>–</u>	<u>22,147</u>

5. Other Trading Activities

	Unrestricted Funds £	Total Funds 2023 £	Unrestricted Funds £	Total Funds 2022 £
Merchandise sales	<u>508</u>	<u>508</u>	<u>906</u>	<u>906</u>

6. Investment Income

	Unrestricted Funds £	Restricted Funds £	Total Funds 2023 £
Bank interest receivable	40	42	82
Dividends receivable	14	–	14
	<u>54</u>	<u>42</u>	<u>96</u>

	Unrestricted Funds £	Restricted Funds £	Total Funds 2022 £
Bank interest receivable	2	7	9
Dividends receivable	–	–	–
	<u>2</u>	<u>7</u>	<u>9</u>

7. Other Income

	Unrestricted Funds £	Total Funds 2023 £	Unrestricted Funds £	Total Funds 2022 £
Consultancy fees	<u>2,223</u>	<u>2,223</u>	<u>–</u>	<u>–</u>

The British Porphyria Association

Notes to the Financial Statements *(continued)*

Year Ended 31 March 2023

8. Costs of Other Trading Activities

	Unrestricted Funds	Total Funds 2023	Unrestricted Funds	Total Funds 2022
	£	£	£	£
Merchandise costs	345	345	1,468	1,468

9. Expenditure on Charitable Activities by Fund Type

	Unrestricted Funds	Restricted Funds	Total Funds 2023
	£	£	£
Costs of charitable activities	37,054	10,733	47,787

	Unrestricted Funds	Restricted Funds	Total Funds 2022
	£	£	£
Costs of charitable activities	21,576	67	21,643

10. Expenditure on Charitable Activities by Activity Type

	Activities undertaken directly	Grant funding of activities	Total funds 2023	Total fund 2022
	£	£	£	£
Costs of charitable activities	47,138	649	47,787	21,643

11. Analysis of Grants

	2023 £	2022 £
Grants to Institutions		
University of Dundee	–	1,000
Grants to Individuals		
Travel bursaries	349	–
Other grants	300	–
	649	–
Total grants	649	1,000

12. Independent Examination Fees

	2023 £	2022 £
Fees payable to the independent examiner for: Independent examination of the financial statements	300	252

The British Porphyria Association

Notes to the Financial Statements *(continued)*

Year Ended 31 March 2023

13. Staff Costs

The average head count of employees during the year was Nil (2022: Nil).

No employee received employee benefits of more than £60,000 during the year (2022: Nil).

14. Trustee Remuneration and Expenses

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

During the year expenses of £2,682 were reimbursed to 5 trustees (2022 - £391 to 2 trustees).

15. Debtors

	2023	2022
	£	£
Gift aid receivable	<u>108</u>	<u>117</u>

16. Creditors: amounts falling due within one year

	2023	2022
	£	£
Accruals and deferred income	<u>300</u>	<u>252</u>

17. Analysis of Charitable Funds

Unrestricted funds

	At 1 April 2022	Income	Expenditure	Transfers	At 31 March 2023
	£	£	£	£	£
General funds	<u>24,545</u>	<u>33,123</u>	<u>(37,399)</u>	<u>5</u>	<u>20,274</u>

	At 1 April 2021	Income	Expenditure	Transfers	At 31 March 2022
	£	£	£	£	£
General funds	<u>24,534</u>	<u>23,055</u>	<u>(23,044)</u>	<u>—</u>	<u>24,545</u>

The British Porphyria Association

Notes to the Financial Statements (continued)

Year Ended 31 March 2023

17. Analysis of Charitable Funds (continued)

Restricted funds

	At 1 April 2022	Income	Expenditure	Transfers	At 31 March 2023
	£	£	£	£	£
Helen Gibbs Fund	17,197	37	(349)	–	16,885
Light Protection Fund	1,025	2	–	(5)	1,022
Festival 2019 fund	1,197	3	–	–	1,200
National Lottery Community Fund	–	9,500	(9,500)	–	–
Disc Medicine	–	884	(884)	–	–
	<u>19,419</u>	<u>10,426</u>	<u>(10,733)</u>	<u>(5)</u>	<u>19,107</u>

	At 1 April 2021	Income	Expenditure	Transfers	At 31 March 2022
	£	£	£	£	£
Helen Gibbs Fund	17,195	2	–	–	17,197
Light Protection Fund	1,020	5	–	–	1,025
Festival 2019 fund	1,264	–	(67)	–	1,197
	<u>19,479</u>	<u>7</u>	<u>(67)</u>	<u>–</u>	<u>19,419</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 2023 £
Current assets	21,458	18,223	39,681
Creditors less than 1 year	(300)	–	(300)
Net assets	<u>21,158</u>	<u>18,223</u>	<u>39,381</u>

	Unrestricted Funds £	Restricted Funds £	Total Funds 2022 £
Current assets	24,797	19,419	44,216
Creditors less than 1 year	(252)	–	(252)
Net assets	<u>24,545</u>	<u>19,419</u>	<u>43,964</u>

The British Porphyria Association

Management Information

Year Ended 31 March 2023

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

The British Porphyria Association

Detailed Statement of Financial Activities

Year Ended 31 March 2023

	2023 £	2022 £
Income and endowments		
Donations		
Donations and subscriptions	16,438	10,019
Gift aid	1,400	1,128
Clinuvel Pharmaceuticals grant	–	1,000
Alnylam grant	10,000	2,000
Recordati Rare Diseases grant	–	5,000
Albert Hunt	–	1,000
Mitsubishi Tanab	2,500	2,000
Disc Medicine	884	–
National Lottery Community Fund	9,500	–
	<u>40,722</u>	<u>22,147</u>
Other trading activities		
Merchandise sales	508	906
Investment income		
Bank interest receivable	82	9
Dividends receivable	14	–
	<u>96</u>	<u>9</u>
Other income		
Consultancy fees	2,223	–
	<u>2,223</u>	<u>–</u>
Total income	<u>43,549</u>	<u>23,062</u>

The British Porphyria Association

Detailed Statement of Financial Activities *(continued)*

Year Ended 31 March 2023

	2023 £	2022 £
Expenditure		
Costs of other trading activities		
Merchandise costs	345	1,468
Costs of charitable activities		
Activities undertaken directly		
BPA events	10,935	168
Festival costs	–	67
Counselling & wellbeing	230	–
Insurance	1,068	821
International conference fees	1,231	–
Trustees' ordinary travel expenses	2,682	391
Ordinary travel expenses	4,152	832
Accountancy fees	300	252
Storage fees	584	532
Printing, postage, stationery and telephone	1,244	1,558
Newsletter	550	441
Advertising and promotional goods	586	48
Subscriptions	346	935
IT and software	519	175
Fundraising	684	225
Administration fees	19,804	14,198
Consultancy fees	2,223	–
	<u>47,138</u>	<u>20,643</u>
Grant funding activities		
Grants given	649	1,000
	<u>47,787</u>	<u>21,643</u>
Expenditure on charitable activities	<u>47,787</u>	<u>21,643</u>
Net expenditure	<u>(4,583)</u>	<u>(49)</u>

THE BRITISH PORPHYRIA ASSOCIATION

England & Wales - Charity number 1089609

Accounts

Charity Registration Number: 1089609

The British Porphyria Association
Financial Statements
For the Year Ending
31 March 2021

JANE ASCROFT ACCOUNTANCY LIMITED

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

The British Porphyria Association

Financial Statements

Year Ended 31 March 2021

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The British Porphyria Association

Trustees' Annual Report

Year Ended 31 March 2021

The trustees present their report and the unaudited financial statements of the charity for the year ended 31 March 2021.

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 BPA commenced the financial year by turning to social media to take part in the International Porphyria Awareness Week in April 2020. Our Fundraising, Awareness and Social Media Working Group worked extremely hard and our bRED campaign was a massive success with great engagement across many countries.

Following the success of the festival in 2019 we had hoped to bring together a similar event in September 2020 in Milton Keynes. However, with all the uncertainty around Covid-19 and the fact that many of our members fall into vulnerable categories, we felt it unwise to pursue a face-to-face gathering. Instead, with the help of grants from Recordati Rare Diseases, Clinuvel and Alnylam Pharmaceuticals, we decided to go virtual and held our first ever online event, Connect 2020. The webinar format of the event integrated our AGM with interactive sessions for children and young people, skin porphyrias and acute porphyrias. These sessions were supported by medical experts who dedicated their time to prepare and pre-record videos for the day as well as taking time out to offer their support and advice in the interactive sessions. Information packs full of information and activity sheets for children were sent out prior to the event. The event was a huge success and as well as reaching out to our UK members, we also had participants from all over the world.

A new treasurer and trustee, Natassja Chadwick, was appointed at the AGM to work alongside Anne Newton for the remainder of the financial year and to take over at the beginning of the financial year, 1 April 2021.

During the financial year ending 31 March 2021, funds were used for administration fees, printing, postage, insurance and membership fees to relevant organisations. Twice yearly newsletters were produced and sent out to our members.

Many events that provide opportunities for our supporters to raise funds were cancelled due to Covid-19, so we turned to social media for our Active 21 campaign during summer 2020. Later in the year, a Christmas bauble fundraiser, our first campaign to sell baubles to raise funds, was a great success.

During the financial year, we continued to take an active part in the development and appraisal of new treatments for porphyria, where there are currently three treatments at various stages of trial or within the regulatory approval processes. We expect to continue our involvement in these and any other forthcoming treatments to ensure the patient voice is heard.

The British Porphyria Association

Trustees' Annual Report *(continued)*

Year Ended 31 March 2021

Activities and Achievements *(continued)*

Grantmaking

It is the policy of the charity to give assistance to sufferers of porphyria to help towards their medical and physical requirements; a grant towards window films for her house was made for a lady with severe HCP.

Financial Review

The BPA funds at 31 March 2021 consist of general funds of £24,534 and restricted funds totalling £19,479: £17,195 in the Helen Gibbs fund for research into acute porphyria, £1,020 in the Light Protection Fund reserved for grants to EPP patients and £1,264 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

The main source of BPA funding is from donations, grants, fundraising and sponsored events. Thank you to all who have made donations and have raised funds for the BPA, particularly during this last difficult year. We really couldn't continue to do the work that we are doing without these amazing efforts.

A thank you also to our sponsors: Alyniam Pharmaceuticals, Recordati Rare Diseases and Clinuvel Pharmaceuticals who helped to fund our Connect 2020 event.

Future Developments

In early 2021 we updated our two-year strategic plan. In addition to our day-to-day running of the charity to fulfil our overarching principles of support, education and research, through our themes of Understand, Connect and Take Control, some of the things we would like to achieve in the coming year are:

- Provide a focus on the mental health of people living with porphyria and facilitate some online sessions with a trained mental health counsellor.
- Hold an EPP camp in Autumn 2022 for children living with EPP to enable them to take part in an adventure break in a safe environment, organised by people who are fully aware of the constraints of EPP (a skin porphyria).

Legacy work from the Festival in 2019 is continuing with video-editing to make the presentations from the day available to enhance knowledge and understanding of porphyria. These are available online to patients, relatives and medical professionals working with porphyria patients.

With the continued uncertainty regarding Covid-19, a decision has been made to hold an online event again in September 2021 incorporating our AGM. We look towards holding a face-to-face (or hybrid) event in 2022.

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.

The British Porphyria Association

Trustees' Annual Report *(continued)*

Year Ended 31 March 2021

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.

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 (Treasurer)
J W Chamberlayne
K E Harris
A Molyneux
R Bennett
N Chadwick (Appointed 19 September 2020)

Independent Examiner Jane Ascroft FCA MA (Cantab)
Enterprise House
Harmire Enterprise Park
Barnard Castle
County Durham
DL12 8XP

The trustees' annual report was approved on 14/5/21 and signed on behalf of the board of trustees by:



J W Chamberlayne
Trustee

The British Porphyria Association

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

Year Ended 31 March 2021

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 2021.

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 8XP

The British Porphyria Association

Statement of Financial Activities

Year Ended 31 March 2021

		Unrestricted funds £	2021 Restricted funds £	Total funds £	2020 Total funds £
	Note				
Income and endowments					
Donations	4	19,898	3,445	23,343	55,889
Other trading activities	5	2,287	–	2,287	–
Investment income	6	11	9	20	80
Total income		<u>22,196</u>	<u>3,454</u>	<u>25,650</u>	<u>55,969</u>
Expenditure					
Expenditure on raising funds:					
Costs of other trading activities	7	1,868	–	1,868	–
Expenditure on charitable activities	8,9	20,064	665	20,729	54,891
Total expenditure		<u>21,932</u>	<u>665</u>	<u>22,597</u>	<u>54,891</u>
Net income		<u>264</u>	<u>2,789</u>	<u>3,053</u>	<u>1,078</u>
Transfers between funds		(40)	40	–	–
Net movement in funds		<u>224</u>	<u>2,829</u>	<u>3,053</u>	<u>1,078</u>
Reconciliation of funds					
Total funds brought forward		24,310	16,650	40,960	39,882
Total funds carried forward		<u>24,534</u>	<u>19,479</u>	<u>44,013</u>	<u>40,960</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 7 to 13 form part of these financial statements.


The British Porphyria Association

Statement of Financial Position

31 March 2021

	Note	2021 £	2020 £
Current Assets			
Debtors	14	26	385
Cash at bank and in hand		<u>44,227</u>	<u>40,815</u>
		44,253	41,200
Creditors: amounts falling due within one year	15	<u>240</u>	<u>240</u>
Net Current Assets		<u>44,013</u>	<u>40,960</u>
Total Assets Less Current Liabilities		<u>44,013</u>	<u>40,960</u>
Net Assets		<u>44,013</u>	<u>40,960</u>
Funds of the Charity			
Restricted funds		19,479	16,650
Unrestricted funds		<u>24,534</u>	<u>24,310</u>
Total charity funds	16	<u>44,013</u>	<u>40,960</u>

These financial statements were approved by the board of trustees and authorised for issue on 14.05.2021, and are signed on behalf of the board by:



A Newton (Treasurer)
Trustee

The notes on pages 7 to 13 form part of these financial statements.

The British Porphyria Association

Notes to the Financial Statements

Year Ended 31 March 2021

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 2021

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 2021

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 2021 £
Donations			
Donations and subscriptions	13,382	–	13,382
Gift aid	1,246	–	1,246
Refund of grant	–	3,445	3,445
Other income	270	–	270
Grants			
Alnylam grant for festival	–	–	–
Alnylam travel grant	–	–	–
Clinuvel Pharmaceuticals grant	1,000	–	1,000
Alnylam grant	2,000	–	2,000
Recordati Rare Diseases grant	2,000	–	2,000
	<u>19,898</u>	<u>3,445</u>	<u>23,343</u>
	Unrestricted Funds £	Restricted Funds £	Total Funds 2020 £
Donations			
Donations and subscriptions	19,638	–	19,638
Gift aid	385	–	385

The British Porphyria Association

Notes to the Financial Statements (continued)

Year Ended 31 March 2021

4. Donations (continued)

	Unrestricted Funds £	Restricted Funds £	Total Funds 2020 £
Grants			
Ainylam grant for festival	–	31,226	31,226
Ainylam travel grant	–	1,640	1,640
Clinuvel Pharmaceuticals grant	3,000	–	3,000
	<u>23,023</u>	<u>32,866</u>	<u>55,889</u>

5. Other Trading Activities

	Unrestricted Funds £	Total Funds 2021 £	Unrestricted Funds £	Total Funds 2020 £
Merchandise sales	<u>2,287</u>	<u>2,287</u>	<u>–</u>	<u>–</u>

6. Investment Income

	Unrestricted Funds £	Restricted Funds £	Total Funds 2021 £
Bank interest receivable	<u>11</u>	<u>9</u>	<u>20</u>

	Unrestricted Funds £	Restricted Funds £	Total Funds 2020 £
Bank interest receivable	<u>38</u>	<u>42</u>	<u>80</u>

7. Costs of Other Trading Activities

	Unrestricted Funds £	Total Funds 2021 £	Unrestricted Funds £	Total Funds 2020 £
Merchandise costs	<u>1,868</u>	<u>1,868</u>	<u>–</u>	<u>–</u>

The British Porphyria Association

Notes to the Financial Statements (continued)

Year Ended 31 March 2021

8. Expenditure on Charitable Activities by Fund Type

	Unrestricted Funds £	Restricted Funds £	Total Funds 2021 £
Costs of charitable activities	<u>20,064</u>	<u>665</u>	<u>20,729</u>

	Unrestricted Funds £	Restricted Funds £	Total Funds 2020 £
Costs of charitable activities	<u>23,013</u>	<u>31,878</u>	<u>54,891</u>

9. Expenditure on Charitable Activities by Activity Type

	Activities undertaken directly £	Grant funding of activities £	Total funds 2021 £	Total fund 2020 £
Costs of charitable activities	<u>20,102</u>	<u>627</u>	<u>20,729</u>	<u>54,891</u>

10. Analysis of Grants

	2021 £	2020 £
Grants to Individuals		
Travel bursaries	–	975
Other grants	<u>627</u>	<u>–</u>
	<u>627</u>	<u>975</u>
Total grants	<u>627</u>	<u>975</u>

11. Independent Examination Fees

	2021 £	2020 £
Fees payable to the independent examiner for: Independent examination of the financial statements	<u>240</u>	<u>240</u>

12. Staff Costs

The average head count of employees during the year was Nil (2020: Nil).

No employee received employee benefits of more than £60,000 during the year (2020: Nil).

The British Porphyria Association

Notes to the Financial Statements *(continued)*

Year Ended 31 March 2021

13. Trustee Remuneration and Expenses

There were no trustees' remuneration or other benefits for the year ended 31st March 2021 nor for the year ending 31st March 2020.

During the year no expenses were reimbursed to trustees (2020 - 3 trustees reimbursed £3,044).

14. Debtors

	2021	2020
	£	£
Gift aid receivable	<u>26</u>	<u>385</u>

15. Creditors: amounts falling due within one year

	2021	2020
	£	£
Accruals	<u>240</u>	<u>240</u>

16. Analysis of Charitable Funds

Unrestricted funds

	At 1 April 2020	Income	Expenditure	Transfers	At 31 March 2021
	£	£	£	£	£
General funds	<u>24,310</u>	<u>22,196</u>	<u>(21,932)</u>	<u>(40)</u>	<u>24,534</u>

	At 1 April 2019	Income	Expenditure	Transfers	At 31 March 2020
	£	£	£	£	£
General funds	<u>24,262</u>	<u>23,061</u>	<u>(23,013)</u>	<u>-</u>	<u>24,310</u>

The British Porphyria Association

Notes to the Financial Statements *(continued)*

Year Ended 31 March 2021

16. Analysis of Charitable Funds *(continued)*

Restricted funds

	At 1 April 2020	Income	Expenditure	Transfers	At 31 March 2021
	£	£	£	£	£
Helen Gibbs Fund	13,743	3,452	–	–	17,195
Light Protection Fund	1,645	2	(627)	–	1,020
Festival 2019 fund	1,262	–	(38)	40	1,264
Aynlam travel grant	–	–	–	–	–
	<u>16,650</u>	<u>3,454</u>	<u>(665)</u>	<u>40</u>	<u>19,479</u>

	At 1 April 2019	Income	Expenditure	Transfers	At 31 March 2020
	£	£	£	£	£
Helen Gibbs Fund	13,718	25	–	–	13,743
Light Protection Fund	1,702	3	(60)	–	1,645
Festival 2019 fund	200	31,240	(30,178)	–	1,262
Aynlam travel grant	–	1,640	(1,640)	–	–
	<u>15,620</u>	<u>32,908</u>	<u>(31,878)</u>	<u>–</u>	<u>16,650</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.

17. Analysis of Net Assets Between Funds

	Unrestricted Funds	Restricted Funds	Total Funds 2021
	£	£	£
Current assets	24,774	19,479	44,253
Creditors less than 1 year	(240)	–	(240)
Net assets	<u>24,534</u>	<u>19,479</u>	<u>44,013</u>

	Unrestricted Funds	Restricted Funds	Total Funds 2020
	£	£	£
Current assets	24,550	16,650	41,200
Creditors less than 1 year	(240)	–	(240)
Net assets	<u>24,310</u>	<u>16,650</u>	<u>40,960</u>

The British Porphyria Association

Management Information

Year Ended 31 March 2021

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

The British Porphyria Association

Detailed Statement of Financial Activities

Year Ended 31 March 2021

	2021 £	2020 £
Income and endowments		
Donations		
Donations and subscriptions	13,382	19,638
Gift aid	1,246	385
Refund of grant	3,445	–
Other income	270	–
Alnylam grant for festival	–	31,226
Alnylam travel grant	–	1,640
Clinuvel Pharmaceuticals grant	1,000	3,000
Alnylam grant	2,000	–
Recordati Rare Diseases grant	2,000	–
	<u>23,343</u>	<u>55,889</u>
Other trading activities		
Merchandise sales	<u>2,287</u>	–
Investment Income		
Bank interest receivable	<u>20</u>	<u>80</u>
Total income	<u><u>25,650</u></u>	<u><u>55,969</u></u>

The British Porphyria Association

Detailed Statement of Financial Activities *(continued)*

Year Ended 31 March 2021

	2021 £	2020 £
Costs of other trading activities		
Merchandise costs	1,868	—
	<u>1,868</u>	<u>—</u>
Expenditure on charitable activities		
<i>Activities undertaken directly</i>		
BPA events	35	1,706
Festival costs	38	21,856
Trustees' travel expenses - Festival	—	746
Committee travel costs - Festival	—	1,190
Insurance	815	720
International conference fees	—	1,082
Trustees' ordinary travel expenses	—	2,298
Ordinary travel expenses	455	4,876
Accountancy fees	240	240
Storage fees	515	515
Printing, postage, stationery and telephone	1,761	1,288
Newsletter	453	568
Advertising and promotional goods	558	45
Subscriptions	416	454
IT and software	850	233
Fundraising	340	1,117
Sundry costs	17	373
Administration fees	13,609	9,152
Administration fees - Festival	—	5,457
	<u>20,102</u>	<u>53,916</u>
<i>Grant funding activities</i>		
Grants given	627	975
	<u>627</u>	<u>975</u>
Expenditure on charitable activities	<u>20,729</u>	<u>54,891</u>
	<u>20,729</u>	<u>54,891</u>
Net income	<u>3,053</u>	<u>1,078</u>
