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

Financial Statements

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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.

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 McGuire, 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.

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.

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.

Trustees' Annual Report (continued)

Year Ended 31 March 2023

Reference and Administrative Details

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

(Served from 15 October 2022 to

Danil Lopukhov 23 February 2023)

Independent Examiner

Jane Ascroft FCA MA (Cantab)

Enterprise House Harmire Enterprise Park

Barnard Castle County Durham DL12 8XP

J W Chamberlayne

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Trustee

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:

- 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
- 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

JAscrafe

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

Statement of Financial Activities

Year Ended 31 March 2023

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

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

Statement of Financial Position

31 March 2023

Current Assets	Note	2023 £	2022 £
Debtors	15	108	117
Cash at bank and in hand	13	39,573	44,099
		39,681	44,216
Creditors: amounts falling due within one year	16	300	252
Net Current Assets		39,381	43,964
Total Assets Less Current Liabilities		39,381	43,964
Net Assets		39,381	43,964
Funds of the Charity			
Restricted funds		19,107	19,419
Unrestricted funds		20,274	24,545
Total charity funds	17	39,381	43,964

These financial statements were approved by the board of trustees and authorised for issue on ...l.1.1.2...3..., and are signed on behalf of the board by:

& Nata

A Newton (Treasurer) Trustee

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.

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.

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			
Alnylam grant	10,000		10,000
Mitsubishi Tanab	2,500	_	2,500
Disc Medicine	_	884	884
National Lottery Community Fund		9,500	9,500
	30,338	10,384	40,722
	Unrestricted	Restricted	Total Funds
	Funds	Funds	2022
	£	£	£
Donations			
Donations and subscriptions	10,019	_	10,019
Gift aid	1,128	-	1,128

Notes to the Financial Statements (continued)

4.	Donations (continued)				
			Unrestricted Funds £	Restricted Funds £	Total Funds 2022 £
	Grants Clinuvel Pharmaceuticals grant Alnylam grant Recordati Rare Diseases grant Albert Hunt Mitsubishi Tanab		1,000 2,000 5,000 1,000 2,000 22,147	- - - - - -	1,000 2,000 5,000 1,000 2,000 22,147
5.	Other Trading Activities				
	Merchandise sales	Unrestricted Funds £ 508	Total Funds 2023 £ 508	Unrestricted Funds £ 906	Total Funds 2022 £ 906
6.	Investment Income	_		_	
	Bank interest receivable Dividends receivable		Unrestricted Funds £ 40 14 54	Restricted Funds £ 42 42	Total Funds 2023 £ 82 14 96
	Bank interest receivable Dividends receivable		Unrestricted Funds £ 2 - 2 - 2	Restricted Funds £ 7 — 7	Total Funds 2022 £ 9 - 9
7.	Other Income				
	Consultancy fees	Unrestricted Funds £ 2,223	Total Funds 2023 £ 2,223	Unrestricted Funds £ 	Total Funds 2022 £

Notes to the Financial Statements (continued)

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	1		
			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 Ty	/pe		
		Activities			
			Grant funding	Total funds	Total fund
		directly	of activities	2023	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			<u>649</u>	1,000
12.	Independent Examination Fees				
				2023	2022
	Ease neighbor to the independent areas!	nor for:		£	£
	Fees payable to the independent exami Independent examination of the financia			300	252

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	108	117
16.	Creditors: amounts falling due within one year		
		2023 £	2022 £
	Accruals and deferred income	300	252

17. Analysis of Charitable Funds

Unrestricted funds

	At				At 31 March
	1 April 2022 £	Income £	Expenditure £	Transfers £	2023 £
General funds	24,545	33,123	(37,399)	5	20,274
	At				At 31 March
	1 April 2021	Income	Expenditure	Transfers	2022
	£	£	£	£	£
General funds	24,534	23,055	(23,044)		24,545

Notes to the Financial Statements (continued)

Year Ended 31 March 2023

17. Analysis of Charitable Funds (continued)

Restricted funds

	At				At 31 March
	1 April 2022	Income	Expenditure	Transfers	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)	_	-
	19,419	10,426	(10,733)	(5)	19,107
		10,420	(10,700)		13,107
	At				At 31 March
	1 April 2021	Income	Expenditure	Transfers	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>`</u>		
	19,479		(67)		19,419
	• • • • • • • • • • • • • • • • • • • •			_	-

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	Restricted	Total Funds
	Funds	Funds	2023
	£	£	£
Current assets	21,458	18,223	39,681
Creditors less than 1 year	(300)		(300)
Net assets	21,158	18,223	39,381
		<u> </u>	· · · · · · · · · · · · · · · · · · ·
	Unrestricted	Restricted	Total Funds
	Funds	Funds	2022
	£	£	£
Current assets	24,797	19,419	44,216
Craditara loca than 1 year	(0.00)		
Creditors less than 1 year	(252)		(252)
Net assets	<u>(252)</u> 24,545	- 19,419	(252) 43,964



Detailed Statement of Financial Activities

	2023 £	2022 £
Income and endowments Donations		~
Donations and subscriptions Gift aid	16,438	10,019
Clinuvel Pharmaceuticals grant	1,400	1,128 1,000
Alnylam grant Recordati Rare Diseases grant	10,000 —	2,000 5,000
Albert Hunt Mitsubishi Tanab	_ 2,500	1,000 2,000
Disc Medicine National Lottery Community Fund	884 9,500	-
,	40,722	22,147
Other trading activities		<u>·</u>
Other trading activities Merchandise sales	<u>508</u>	906
Investment income		
Bank interest receivable Dividends receivable	82 14	9
	96	_9
Other income		
Consultancy fees	2,223	
Total income	43,549	23,062
		

Detailed Statement of Financial Activities (continued)

	2023 £	2022 £
Expenditure	L	L
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	
	47,138	20,643
Grant funding activities		
Grants given	649	1,000
give.		1,000
Expenditure on charitable activities	47,787	21,643
•	,.	
Net expenditure	(4,583)	
net expenditule	(4,583)	(49)