Charity Registration Number: 1089609

The British Porphyria Association
Financial Statements
For the Year Ending
31 March 2022

JANE ASCROFT ACCOUNTANCY LIMITED

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

Financial Statements

Year Ended 31 March 2022

	Page
Trustees' Annual Report	1
Independent Examiner's Report to the Trustees	6
Statement of Financial Activities	7
Statement of Financial Position	8
Notes to the Financial Statements	9
The Following Page Does Not Form Part of the Financial Statements	
Detailed Statement of Financial Activities	17

Trustees' Annual Report

Year Ended 31 March 2022

The trustees present their report and the unaudited financial statements of the charity for the year ended 31 March 2022.

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.

Trustees' Annual Report (continued)

Year Ended 31 March 2022

Activities and Achievements

The BPA commenced the financial year by taking part in the International Porphyria Awareness Week on social media in April 2021. Our Fundraising, Awareness and Social Media Working Group worked extremely hard and our Porphyria Awareness campaign was a huge success with great engagement across many countries. We also had for sale Porphyria Awareness hoodies and facemasks.

With the continued uncertainty around Covid-19 we made the decision not to hold a face-to-face event again in 2021 and following the success of our Connect 2020 online event, we held Connect 2021 virtually on 9 October 2021. The webinar event started with the AGM followed by the opportunity for attendees to meet porphyria specialists from across the UK with representatives from centres in Cardiff, Salford, Edinburgh and Dundee. The next part of the event focused on the new drug development process and the importance of research trials with Prof Jean-Charles Deybach and Dr Mark Farrar. Prof Deybach provided an encouraging update about research into the porphyrias, while Dr Farrar explained how patients can get involved in research. There were talks from expert patients with accounts of their patient journey and also interactive sessions. The final part of the day focused on counselling and wellbeing with talks from a counsellor and a yoga teacher/wellbeing educator, giving holistic approaches to managing life, pain and porphyria, as well as tips on how best to care for your body and mind. The event was sponsored by Alnylam Pharmaceuticals, Clinuvel, Mitsubishi Tanabe and Recordati Rare Diseases.

Packs full of information and activity sheets for children were sent out prior to the event. The event was again a huge success and as well as reaching out to our UK members, we also had participants from all over the world.

During the financial year ending 31 March 2022, 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.

Following the success of the 2020 Christmas bauble fundraising campaign, we decided to add another bauble and Christmas cards to our successful 2021 Christmas fundraiser campaign.

During the financial year, we continued to take an active part in the development and appraisal of new treatments for porphyria. In October 2021 one of the new treatments for acute porphyria, Givlaari was finally approved for use on the NHS. NICE issued draft guidance recommending the use of Givlaari on the NHS in England for the treatment of severe recurrent attacks of acute porphyria with the first patients to receive the treatment from late February 2022.

We continue to be involved with the drug approval process and research into 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 appraisal.

Due to unforeseen circumstances our new treasurer and trustee, Natassja Chadwick made the decision to resign as treasurer early in her appointment in 2021. Natassja is still happy to continue as a trustee. Anne Newton stepped back into the role as acting treasurer until a new treasurer was appointed.

As the 2021-22 financial year ends, we are finalising the process of appointing Danil Lopukhov as our new treasurer and as a trustee. We are delighted that Danil has accepted the role and will commence his position for the 2022-23 financial year. We are confident that his experience and expertise will be a great asset to the charity.

Trustees' Annual Report (continued)

Year Ended 31 March 2022

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 have been allocated to assist 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. To ensure that all eligible patients, who may be unable to cover the cost of travelling to a porphyria centre, are able to have the treatment, patients in need are able to apply to the BPA for a Helen Gibbs Grant of up to £50 travel and £50 overnight stay per visit (six visits). After the first six months, patients will receive their treatment at home.

Financial Review

The BPA funds at 31 March 2022 consist of general funds of £24,545 and restricted funds totalling £19,419: £17,197 in the Helen Gibbs fund for research into acute porphyria, £1,025 in the Light Protection Fund reserved for grants to EPP patients and £1,197 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 sponsors, Alnylam Pharmaceuticals, Recordati Rare Diseases, Clinuvel Pharmaceuticals and Mitsubishi Tanabe helped to fund our Connect 2021 event. 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.

Recordati Rare Diseases also provided a grant to help get our Wellbeing project off the ground. Together with a grant from the Albert Hunt Trust in August 2021, we were able to get the project started.

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 2022-23 financial year.

Trustees' Annual Report (continued)

Year Ended 31 March 2022

Future Developments

In early 2021 we updated our two-year strategic plan. In addition to the 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 this project has now started with the first patients starting to receive support in Spring 2022.
- Our plan to hold an EPP camp in Autumn 2022 for children living with EPP has been changed to be a Porphyria Activity Day. The aim is for all EPP patients to be able to get involved in an outdoor physical activity safely, as the day will be organised by people who are fully aware of the constraints of EPP (a light sensitivity porphyria). Although there is a focus on EPP patients, all porphyria patients and their families are welcome to attend. This event, Connect Alfresco, will be held in Leeds on 15 October 2022 and will also incorporate the BPA AGM.
- We are planning to hold a hybrid event on 15 May 2022 in Dundee with both a face-to-face element and online streaming for those members who are unable to attend in person.

The BPA plan to send representatives to the International Congress on Porphyrins and Porphyrias which is being held in Sofia, Bulgaria, 4-7 September 2022. This two-yearly event brings together patients, researchers, experts and scholars for networking and learning from the best in the field of porphyria. The BPA are planning to attend both the International Patient Day, held on the first day, and also the main scientific event and provide an update to our members of any new and exciting research developments.

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.

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.

Trustees' Annual Report (continued)

Year Ended 31 March 2022

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

Independent Examiner

Jane Ascroft FCA MA (Cantab)

16/5/22 and signed on behalf of the board of

Enterprise House Harmire Enterprise Park

Barnard Castle County Durham DL12 8XT

The trustees' annual report was approved on . trustees by:

M Champerlay

J W Chamberlayne

Trustee

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

Year Ended 31 March 2022

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 2022.

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
- 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

UASCITETE.

Statement of Financial Activities

Year Ended 31 March 2022

		Unrestricted	2022 Restricted		2021
	Note	funds £	funds £	Total funds £	Total funds
Income and endowments					
Donations	4	22,147	_	22,147	23,343
Other trading activities	5	906	_	906	2,287
Investment income	6	2	7	9	20
Total income		23,055	7	23,062	25,650
Expenditure Expenditure on raising funds:	7	4.460		4.400	4.000
Costs of other trading activities	•	1,468	-	1,468	1,868
Expenditure on charitable activities	8,9	<u>21,576</u>	<u>67</u>	21,643	20,729
Total expenditure		23,044	67	23,111	22,597
Net (expenditure)/income and net					
movement in funds		11	(60)	(49)	3,053
Reconciliation of funds					
Total funds brought forward		24,534	19,479	44,013	40,960
Total funds carried forward		24,545	19,419	43,964	44,013

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 2022

	Note	2022 £	2021 £
Current Assets Debtors	14	117	26
Cash at bank and in hand		44,099	44,227
		44,216	44,253
Creditors: amounts falling due within one year	15	252	240
Net Current Assets		43,964	44,013
Total Assets Less Current Liabilities		43,964	44,013
Net Assets		43,964	44,013
Funds of the Charity			
Restricted funds		19,419	19,479
Unrestricted funds		24,545	24,534
Total charity funds	16	43,964	44,013

A Newton (Treasurer)

& Noutan

Trustee

Notes to the Financial Statements

Year Ended 31 March 2022

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 2022

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 2022

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 2022 £
Donations			
Donations and subscriptions	10,019	_	10,019
Gift aid	1,128	_	1,128
Refund of grant	, <u> </u>	_	-
Other income	_	_	
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
	22,147	_	22,147
	Unrestricted	Restricted	Total Funds
	Funds	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

Notes to the Financial Statements (continued)

Year Ended 31 March 2022

4.	Donations (continued)				
	Grants Clinuvel Pharmaceuticals grant Alnylam grant Recordati Rare Diseases grant Albert Hunt		Unrestricted Funds £ 1,000 2,000 2,000	Restricted Funds £ - - -	Total Funds 2021 £ 1,000 2,000 2,000
	Mitsubishi Tanab		19,898	3,445	23,343
5.	Other Trading Activities				
	Merchandise sales	Unrestricted Funds £ 906	Total Funds 2022 £ 906	Unrestricted Funds £ 2,287	Total Funds 2021 £ 2,287
6.	Investment Income	-			
0.	Bank interest receivable		Unrestricted Funds £	Restricted Funds £	Total Funds 2022 £ 9
	Bank interest receivable		Unrestricted Funds £ 11	Restricted Funds £ 9	Total Funds 2021 £ 20
7.	Costs of Other Trading Activities				
	Merchandise costs	Unrestricted Funds £ 1,468	Total Funds 2022 £ 1,468	Unrestricted Funds £ 1,868	Total Funds 2021 £ 1,868

Notes to the Financial Statements (continued)

Year Ended 31 March 2022

8.	Expenditure	on Charitable	Activities	by Fund Type

	Unrestricted	Restricted	Total Funds
	Funds	Funds	2022
	£	£	£
Costs of charitable activities	21,576	67	21,643
	* *** * Apple		
	Unrestricted	Restricted	Total Funds
	Funds	Funds	2021
	£	£	£
Costs of charitable activities	20,064	665	20,729

9. Expenditure on Charitable Activities by Activity Type

	Activities			
	undertaken (Grant funding	Total funds	Total fund
	directly	of activities	2022	2021
	£	£	£	£
Costs of charitable activities	20,643	1,000	21,643	20,729

10. Analysis of Grants

	2022 £	2021 £
Grants to Institutions University of Dundee	1,000	-
Grants to Individuals Other grants	-	627
Total grants	1,000	627

11. Independent Examination Fees

	2022	2021
	£	£
Fees payable to the independent examiner for:		
Independent examination of the financial statements	252	240

12. Staff Costs

The average head count of employees during the year was Nil (2021: Nil).

No employee received employee benefits of more than £60,000 during the year (2021: Nil).

Notes to the Financial Statements (continued)

Year Ended 31 March 2022

13. Trustee Remuneration and Expenses

There were no trustees' remuneration or other benefits for the year ended 31st March 2022 nor for the year ending 31st March 2022.

During the year expenses of £391 were reimbursed to 2 trustees (2021 - no expenses).

14. Debtors

	2022	2021
	£	£
Gift aid receivable	117	26

15. Creditors: amounts falling due within one year

	2022	2021
	£	£
Accruals and deferred income	252	240

16. Analysis of Charitable Funds

Unrestricted funds

Onrestricted funds	At				At 31 March
	1 April 2021	Income	Expenditure	Transfers	2022
	£	£	£	£	£
General funds	24,534	23,055	(23,044)	_	24,545

	At				At 31 March
	1 April 2020	Income	Expenditure	Transfers	2021
	£	£	£	£	£
General funds	24,310	22,196	(21,932)	(40)	24,534
			· ——	-	# ** * * * * * * * * * * * * * * * * *

Notes to the Financial Statements (continued)

Year Ended 31 March 2022

16. Analysis of Charitable Funds (continued)

Restricted funds

Helen Gibbs Fund Light Protection Fund Festival 2019 fund	At 1 April 2021 £ 17,195 1,020 1,264 19,479	Income £ 2 5 — 7	Expenditure £ - (67) (67)	Transfers £	At 31 March 2022 £ 17,197 1,025 1,197 19,419
Helen Gibbs Fund Light Protection Fund Festival 2019 fund	At 1 April 2020 £ 13,743 1,645 1,262 16,650	Income £ 3,452 2 ——————————————————————————————————	Expenditure £ (627) (38) (665)	Transfers £ - 40 40	At 31 March 2021 £ 17,195 1,020 1,264 19,479

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	Restricted	Total Funds
	Funds	Funds	2022
	£	£	£
Current assets	24,797	19,419	44,216
Creditors less than 1 year	(252)		(252)
Net assets	24,545	19,419	43,964
		-	
	Unrestricted	Restricted	Total Funds
	Funds	Funds	2021
	£	£	£
Current assets	24,774	19,479	44,253
Creditors less than 1 year	(240)	_	(240)
Net assets	24,534	19,479	44,013
		•	



Detailed Statement of Financial Activities

Year Ended 31 March 2022

	2022	2021
Income and endowments	£	£
Donations		
Donations and subscriptions	10,019	13,382
Gift aid .	1,128	1,246
Refund of grant	_	3,445
Other income Clinuvel Pharmaceuticals grant	1 000	270
Alnylam grant	1,000 2,000	1,000 2,000
Recordati Rare Diseases grant	5,000	2,000
Albert Hunt	1,000	_,000
Mitsubishi Tanab	2,000	_
		22.242
	22,147	23,343
Other trading activities		
Merchandise sales	906	2,287
		· · · · · ·
Investment income	•	
Bank interest receivable	_9	<u>20</u>
Total income		05.050
i otal income	23,062	25,650
Expenditure		
Costs of other trading activities		
Merchandise costs	1,468	1,868
Expenditure on charitable activities		
Activities undertaken directly		
BPA events	168	35
Festival costs	67	38
Insurance	821	815
Trustees' ordinary travel expenses	391	
Ordinary travel expenses Accountancy fees	832	455
Storage fees	252 532	240 515
Printing, postage, stationery and telephone	1,558	1,761
Newsletter	441	453
Advertising and promotional goods	48	558
Subscriptions	935	416
T and software	175	850
Fundraising	225	340
Sundry costs Administration fees	_	17
Administration fees	<u>14,198</u>	13,609
	20,643 ———	20,102
Grant funding activities		
Grants given	1,000	627
Expenditure on charitable activities	21.642	20.720
	21,643	20,729
Net (expenditure)/income	(49)	3,053
\	(40)	3,000