

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**

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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

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### 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: Alnylam 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

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## 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**

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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				
<b>Income and endowments</b>					
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
<b>Total income</b>		<u>22,196</u>	<u>3,454</u>	<u>25,650</u>	<u>55,969</u>
<b>Expenditure</b>					
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
<b>Total expenditure</b>		<u>21,932</u>	<u>665</u>	<u>22,597</u>	<u>54,891</u>
<b>Net income</b>		<u>264</u>	<u>2,789</u>	<u>3,053</u>	<u>1,078</u>
Transfers between funds		(40)	40	–	–
<b>Net movement in funds</b>		<u>224</u>	<u>2,829</u>	<u>3,053</u>	<u>1,078</u>
<b>Reconciliation of funds</b>					
Total funds brought forward		24,310	16,650	40,960	39,882
<b>Total funds carried forward</b>		<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 £
<b>Current Assets</b>			
Debtors	14	26	385
Cash at bank and in hand		44,227	40,815
		<u>44,253</u>	<u>41,200</u>
<b>Creditors: amounts falling due within one year</b>	15	240	240
<b>Net Current Assets</b>		<u>44,013</u>	<u>40,960</u>
<b>Total Assets Less Current Liabilities</b>		<u>44,013</u>	<u>40,960</u>
<b>Net Assets</b>		<u>44,013</u>	<u>40,960</u>
<b>Funds of the Charity</b>			
Restricted funds		19,479	16,650
Unrestricted funds		24,534	24,310
<b>Total charity funds</b>	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

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### 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

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### 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 £
<b>Donations</b>			
Donations and subscriptions	13,382	–	13,382
Gift aid	1,246	–	1,246
Refund of grant	–	3,445	3,445
Other income	270	–	270
<b>Grants</b>			
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 £
<b>Donations</b>			
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 £
<b>Grants</b>			
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 £
<b>Grants to Individuals</b>		
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
Alnylam 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
Alnylam 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)
<b>Net assets</b>	<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)
<b>Net assets</b>	<u>24,310</u>	<u>16,650</u>	<u>40,960</u>

# **The British Porphyria Association**

## **Management Information**

**Year Ended 31 March 2021**

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**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

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	2021 £	2020 £
<b>Income and endowments</b>		
<b>Donations</b>		
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>
 <b>Other trading activities</b>		
Merchandise sales	<u>2,287</u>	<u>–</u>
 <b>Investment Income</b>		
Bank interest receivable	<u>20</u>	<u>80</u>
 <b>Total income</b>	<u><u>25,650</u></u>	<u><u>55,969</u></u>

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# The British Porphyria Association

## Detailed Statement of Financial Activities *(continued)*

Year Ended 31 March 2021

	2021 £	2020 £
<b>Costs of other trading activities</b>		
Merchandise costs	1,868	—
<b>Expenditure on charitable activities</b>		
<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>
<b>Grant funding activities</b>		
Grants given	627	975
	<u>20,729</u>	<u>54,891</u>
<b>Net income</b>	<u>3,053</u>	<u>1,078</u>