

Charity Registration Number: 1089609

The British Porphyria Association
Financial Statements
For the Year Ending
31 March 2019

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 2019

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The British Porphyria Association

Trustees' Annual Report

Year Ended 31 March 2019

The trustees present their report and the unaudited financial statements of the charity for the year ended 31 March 2019.

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.

The British Porphyria Association

Trustees' Annual Report *(continued)*

Year Ended 31 March 2019

Activities and Achievements

During the 2018-19 financial year, the BPA has continued to develop and flourish in its activities. A new committee member has brought a younger perspective to the activities of the BPA. This has helped us to improve our focus on young patients affected by the porphyrias, which is one of our priority objectives in our two-year strategic plan.

The profile of the BPA and its influence in national and international networks has vastly expanded with committee members being highly involved in relationships with the British and Irish Porphyria Network (BIPNET), the National Acute Porphyria Service (NAPS), the Porphyria Patient International umbrella organisation and the European Porphyria Network (EPNET). Involvement in these networks brings vast benefits to patients and we are able to be more reactive and up to date with the information that we share with our members. Ultimately, this broadens our capacity to support patients.

During the last financial year, a large proportion of our funds have been used for administrator fees, printing, postage, insurance and membership fees to relevant organisations. Funds have been used to host our annual Porphyria Open Day and our Autumn Conference and AGM, including venue fees and other relevant expenses, such as paying speaker and committee travel expenses and also bursaries to help members attend these events. Funds have also been used for committee members to attend the national and international meetings and events mentioned above.

Twice yearly newsletters were produced as well as further print runs of our existing information leaflets. Six charity places for the 2019 Great North Run have also been purchased together with additional merchandise to raise awareness of porphyria and increase our profile at fundraising events.

On behalf of our members we have continued to take part in the appraisal process for a new treatment for people with erythropoietic protoporphyria – Afamelanotide (Scenesse). The efforts to make an impact on the NICE decision have been extensive and have taken considerable BPA time and resources for numerous committee members. This process is ongoing and we do not yet know the eventual outcome. The steep learning curve experienced while being part of the regulatory and financial reimbursement process in the UK, has vastly enhanced BPA knowledge in this field. This will be instrumentally beneficial for patients, when the next new drug for acute porphyria (Givosiran) comes to this stage of development – expected in 2019-20. Furthermore, involvement in the process has also served to develop the understanding of EPP and the intricacies in the way patients are affected. Thereby further improving the way we can respond to and support patients.

Another stream of work has seen the BPA involved in the development of patient perspective studies into the acute porphyrias, which will gain further insight into the burden of illness of patients and help to guide the way forward for treatments and quality of life improvements for our members.

We are continuing to develop our social media presence and are happy to report a continued increase in numbers of members attending our meetings. We have a new BPA blog designed to engage younger patients and we have also started a new Instagram page on social media to meet the demands of a young group of patients.

Grantmaking

It is the policy of the charity to give assistance to sufferers of porphyria to help towards their medical and physical requirements and a grant has been made from the Light Protection Fund to help a member purchase light projective clothing. Funds have also been used for bursaries to help patients attend our Open Day and AGM and Conference.

The British Porphyria Association

Trustees' Annual Report (*continued*)

Year Ended 31 March 2019

Financial Review

The BPA funds at 31 March 2019 consist of general funds of £24,262 and restricted funds totalling £15,620: £13,718 in the Helen Gibbs fund for research into acute porphyria, £1,702 in the Light Protection Fund reserved for grants to EPP patients and £200 towards the Festival 2019.

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. A huge thank you to all who are raising funds for the BPA we couldn't continue to do the work that we without these amazing fund raising efforts and donations.

Within the 2018-19 financial year, a grant of £3,000 was received from Orphan Europe to help towards our patient meeting in Dublin in June 2019 and Porphyria Festival in October 2019 to celebrate our 20th anniversary.

We are also pleased to report that we have been successful in our application for an Advocacy Impact Grant from Alnylam Pharmaceuticals in the sum of \$38,612.42 US dollars towards holding our new and unique Porphyria Festival. These funds will be processed to the BPA in the 2019-20 financial year. We have also secured a grant from Clinovel Pharmaceuticals for £3,000 to help towards 2019-20 costs.

Future Developments

In 2018, we updated our two-year strategic plan. As well as our usual activities into supporting and educating patients, families and medical professionals about porphyria and encouraging research, we recognised a gap in support for the under 30s. We decided that future plans should concentrate on engaging the 18-30 age group and being more inclusive for the under 18s group. The upcoming 20th Anniversary Porphyria Festival is being designed to be immersive and engaging to a younger cohort of porphyria patients and also to focus on the poorly met mental health and well-being needs of a group with a long term health condition.

Marketing/video materials obtained at the festival will be used to enhance porphyria knowledge for medical and other professionals working with porphyria patients including pain specialists, A&E doctors, gastroenterologists, obstetricians and gynaecological specialists, teenage paediatrics, dermatologists, GPs, dieticians as well as universities and schools, involving a whole new demographic of people who may benefit from the event as well as increasing porphyria awareness and potentially easing the route to diagnosis.

The British Porphyria Association

Trustees' Annual Report *(continued)*

Year Ended 31 March 2019

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 (Appointed 19 April 2018)

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 10/8/19 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 2019

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 2019.

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 2019

		Unrestricted funds £	2019 Restricted funds £	Total funds £	2018 Total funds £
	Note				
Income and endowments					
Donations	4	18,813	2,000	20,813	37,197
Investment income	5	51	31	82	30
Total income		<u>18,864</u>	<u>2,031</u>	<u>20,895</u>	<u>37,227</u>
Expenditure					
Expenditure on charitable activities	6,7	<u>27,239</u>	<u>2,000</u>	<u>29,239</u>	<u>28,483</u>
Total expenditure		<u>27,239</u>	<u>2,000</u>	<u>29,239</u>	<u>28,483</u>
Net (expenditure)/income and net movement in funds					
		<u>(8,375)</u>	<u>31</u>	<u>(8,344)</u>	<u>8,744</u>
Reconciliation of funds					
Total funds brought forward		<u>32,637</u>	<u>15,589</u>	<u>48,226</u>	<u>39,482</u>
Total funds carried forward		<u>24,262</u>	<u>15,620</u>	<u>39,882</u>	<u>48,226</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 8 to 13 form part of these financial statements.

The British Porphyria Association

Statement of Financial Position

31 March 2019

	Note	2019 £	2018 £
Current Assets			
Cash at bank and in hand		40,122	48,466
Creditors: amounts falling due within one year	12	<u>240</u>	<u>240</u>
Net Current Assets		<u>39,882</u>	<u>48,226</u>
Total Assets Less Current Liabilities		<u>39,882</u>	<u>48,226</u>
Net Assets		<u>39,882</u>	<u>48,226</u>
Funds of the Charity			
Restricted funds		15,620	15,589
Unrestricted funds		<u>24,262</u>	<u>32,637</u>
Total charity funds	13	<u>39,882</u>	<u>48,226</u>

These financial statements were approved by the board of trustees and authorised for issue on ~~19/3/19~~, and are signed on behalf of the board by:



A Newton (Treasurer)
Trustee

The notes on pages 8 to 13 form part of these financial statements.

The British Porphyria Association

Notes to the Financial Statements

Year Ended 31 March 2019

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 2019

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 2019

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 2019 £
Donations			
Donations and subscriptions	18,171	2,000	20,171
Gift aid	642	–	642
Donation from Helen Gibbs Trust Fund	–	–	–
	<u>18,813</u>	<u>2,000</u>	<u>20,813</u>

	Unrestricted Funds £	Restricted Funds £	Total Funds 2018 £
Donations			
Donations and subscriptions	31,776	116	31,892
Gift aid	660	–	660
Donation from Helen Gibbs Trust Fund	–	4,645	4,645
	<u>32,436</u>	<u>4,761</u>	<u>37,197</u>

5. Investment Income

	Unrestricted Funds £	Restricted Funds £	Total Funds 2019 £
Bank interest receivable	<u>51</u>	<u>31</u>	<u>82</u>

The British Porphyria Association

Notes to the Financial Statements *(continued)*

Year Ended 31 March 2019

5. Investment Income *(continued)*

	Unrestricted Funds £	Restricted Funds £	Total Funds 2018 £
Bank interest receivable	<u>19</u>	<u>11</u>	<u>30</u>

6. Expenditure on Charitable Activities by Fund Type

	Unrestricted Funds £	Restricted Funds £	Total Funds 2019 £
Costs of charitable activities	<u>27,239</u>	<u>2,000</u>	<u>29,239</u>

	Unrestricted Funds £	Restricted Funds £	Total Funds 2018 £
Costs of charitable activities	<u>21,983</u>	<u>6,500</u>	<u>28,483</u>

7. Expenditure on Charitable Activities by Activity Type

	Activities undertaken directly £	Grant funding of activities £	Total funds 2019 £	Total fund 2018 £
Costs of charitable activities	<u>28,915</u>	<u>324</u>	<u>29,239</u>	<u>28,483</u>

8. Analysis of Grants

	2019 £	2018 £
Grants to Institutions		
University of Dundee	–	6,500
Grants to Individuals		
Travel bursaries	124	47
Other grants	<u>200</u>	<u>–</u>
	<u>324</u>	<u>47</u>
Total grants	<u>324</u>	<u>6,547</u>

9. Independent Examination Fees

	2019 £	2018 £
Fees payable to the independent examiner for: Independent examination of the financial statements	<u>240</u>	<u>300</u>

The British Porphyria Association

Notes to the Financial Statements *(continued)*

Year Ended 31 March 2019

10. Staff Costs

The average head count of employees during the year was Nil (2018: Nil).

No employee received employee benefits of more than £60,000 during the year (2018: Nil).

11. Trustee Remuneration and Expenses

There were no trustees' remuneration or other benefits for the year ended 31st March 2019 nor for the year ending 31st March 2018.

During the year 4 trustees were reimbursed expenses totalling £2,115 (2018 - £2,253).

12. Creditors: amounts falling due within one year

	2019	2018
	£	£
Accruals and deferred income	<u>240</u>	<u>240</u>

13. Analysis of Charitable Funds

Unrestricted funds

	At 1 April 2018	Income	Expenditure	At 31 March 2019
	£	£	£	£
General funds	<u>32,637</u>	<u>18,864</u>	<u>(27,239)</u>	<u>24,262</u>

Restricted funds

	At 1 April 2018	Income	Expenditure	At 31 March 2019
	£	£	£	£
Helen Gibbs Fund	13,691	27	–	13,718
Light Protection Fund	1,898	4	(200)	1,702
Festival 2019 fund	–	<u>2,000</u>	<u>(1,800)</u>	<u>200</u>
	<u>15,589</u>	<u>2,031</u>	<u>(2,000)</u>	<u>15,620</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.

The British Porphyria Association

Notes to the Financial Statements *(continued)*

Year Ended 31 March 2019

14. Analysis of Net Assets Between Funds

	Unrestricted Funds £	Restricted Funds £	Total Funds 2019 £	Total Funds 2018 £
Current assets	24,502	15,620	40,122	48,466
Creditors less than 1 year	(240)	–	(240)	(240)
Net assets	<u>24,262</u>	<u>15,620</u>	<u>39,882</u>	<u>48,226</u>

The British Porphyria Association

Management Information

Year Ended 31 March 2019

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

The British Porphyria Association

Detailed Statement of Financial Activities

Year Ended 31 March 2019

	2019 £	2018 £
Income and endowments		
Donations		
Donations and subscriptions	20,171	31,892
Gift aid	642	660
Donation from Helen Gibbs Trust Fund	–	4,645
	<u>20,813</u>	<u>37,197</u>
Investment income		
Bank interest receivable	82	30
	<u>82</u>	<u>30</u>
Total income	<u>20,895</u>	<u>37,227</u>
Expenditure		
<i>Activities undertaken directly</i>		
BPA events	7,538	1,836
Insurance	627	564
Trustees' travel expenses	2,115	2,253
Travel expenses	2,949	4,361
Accountancy fees	240	360
Printing, postage, stationery and telephone	1,639	1,109
Newsletter	555	825
Advertising and promotional goods	1,042	1,491
Subscriptions	472	311
IT and software	217	130
Fundraising	480	1,580
Sundry costs	502	–
Administration fees	10,539	5,826
International conference fees	–	1,290
	<u>28,915</u>	<u>21,936</u>
<i>Grant funding activities</i>		
Grants given	324	6,547
	<u>324</u>	<u>6,547</u>
Total expenditure	<u>29,239</u>	<u>28,483</u>
Net (expenditure)/income	<u>(8,344)</u>	<u>8,744</u>
