

Charity Registration Number: 1089609

The British Porphyria Association
Financial Statements
For the Year Ending
31 March 2020

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 2020

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The British Porphyria Association

Trustees' Annual Report

Year Ended 31 March 2020

The trustees present their report and the unaudited financial statements of the charity for the year ended 31 March 2020.

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 celebrated its 20th anniversary in 2019. In recognition of the occasion, plans were made to hold a Porphyria Festival. We were successful in our application for a substantial grant in the Alnylam Pharmaceuticals' Advocacy for Impact Competitive Grant Programme. This grant, together with a grant from Recordati Rare Diseases (formerly Orphan Europe) (received in the 2018-2019 financial year) and an unrestricted grant from Clinuvel (UK) Limited enabled us to go ahead with our plans to put on a truly unique event like nothing previously held in the field of porphyria anywhere else in the world.

The Porphyria Festival was held at the Science and Industry Museum, Manchester in October 2019 and was primarily aimed at engaging younger patients and their families, as well as focusing on the poorly met mental health and wellbeing needs of porphyria patients. The event was a huge success and was attended by 169 people of all ages. With a diverse content to cover acute and cutaneous porphyrias, as well as health and wellbeing and pain management, in addition to workshops and entertainment, we managed to engage and support all ages and family members affected by porphyria.

We also held our first patient conference in Ireland in June 2019 which was supported by the above-mentioned grant from Recordati Rare Diseases. The event held in Dublin was also a huge success with a total of 44 people attending from all over Ireland.

2019 was also the year for the International Congress on Porphyrins and Porphyrias (ICPP) in Milan in September. The international scientific meeting, held every two years, was attended by over 500 attendees from 59 countries. The day before the main event an International Patient Day was also held. The BPA were able to send six committee members to the Patient Day (with three contributing to presentations on the day), while five committee members stayed on to attend the three-day main scientific conference. Travel costs and conference fees were partially covered by speaker dispensations, a grant from Alnylam Pharmaceuticals, an unrestricted grant from Clinuvel (UK) Limited and the European Porphyria Network (Epnnet).

The British Porphyria Association

Trustees' Annual Report *(continued)*

Year Ended 31 March 2020

Activities and Achievements *(continued)*

In the months prior to ICPP, the BPA had been involved with work between other international porphyria patient organisations to form an umbrella organisation which would support and represent all porphyrias across the world. It was agreed that it should be based in Europe and in an English-speaking country. BPA Chair, John Chamberlayne, helped draft a constitution, apply to the UK Charities Commission, and arrange a banking solution. Before the formal ICPP programme began in Milan, the Global Porphyria Advocacy Coalition (GPAC) held its inaugural meeting at which the organisation was formalised. The first executives were elected and Sue Burrell was elected to be the President of GPAC for a 2-year term. Since then, GPAC has grown to include 24 member organisations, representing 33 countries from around the world. GPAC's members will join working groups to focus on the following key areas: access to treatment, support, research, awareness and education and it is important for our members that the BPA are involved in this exciting global venture.

Two BPA committee members are also involved with the European Porphyria Network (Epnnet). Epnnet is a clinician-led, non-profit association which aims to improve healthcare services for porphyria patients. Liz Gill is the international patient representative on the Epnnet Board while Antony Fearn is involved with the Epnnet website working group.

We are continuing to take part in the appraisal for a new treatment for people with erythropoietic protoporphyria, called Scenesse (Afamelanotide). We also expect to be involved in the approval processes for other forthcoming new treatments to ensure the patient voice is heard.

During the last financial year, funds have been used for administration fees, printing, postage, insurance and membership fees to relevant organisations. Twice yearly newsletters have been produced and sent out to our members. Further print runs of our existing information leaflets have also been done, together with additional merchandise and festival specific merchandise purchased. Funds have also been used for committee members to attend national and international meetings and events.

Grantmaking

It is the policy of the charity to give assistance to sufferers of porphyria to help towards their medical and physical requirements; however, no grants have been made for this during 2019-20 (2018 - 19 - One grant was made).

The BPA this year supported members to attend our Porphyria Festival with several travel bursaries being awarded.

The British Porphyria Association

Trustees' Annual Report *(continued)*

Year Ended 31 March 2020

Financial Review

The BPA funds at 31 March 2020 consist of general funds of £24,310 and restricted funds totalling £16,650: £13,743 in the Helen Gibbs fund for research into acute porphyria, £1,645 in the Light Protection Fund reserved for grants to EPP patients and £1,262 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. A huge thank you to all our sponsors: Alnylam Pharmaceuticals, Recordati Rare Diseases (formerly Orphan Europe), Clinuvel Pharmaceuticals, and all who have made donations and are raising funds for the BPA. We really couldn't continue to do the work that we are doing without these amazing efforts.

Future Developments

In early 2020 we updated our two-year strategic plan. The main focus points for continuing to develop the charity are to:

- bring more volunteers into the charity with specific skills to help us achieve great things
- seek a new treasurer as our current treasurer, Anne Newton, is looking to step down after many years in the role
- generate increased engagement and be more accessible to children and young people
- encourage and support research into finding better treatments for all of the porphyrias
- maintain and foster networks in the UK, Europe and globally.

Work from the Festival is continuing, with video-editing to make available the talks and events from the day, to enhance knowledge of porphyria. These will be made available online and will also be made available to medical professionals working with porphyria patients.

In line with one of our aims, we have a newly formed sub-committee - the Fundraising, Awareness and Social Media Working Group, and with the help of three new members it aims to concentrate on increasing and strengthening our presence and approach on social media platforms to ensure we are fully engaged across all age groups. An initial online event was planned for Porphyria Awareness week in April 2020. The group have some exciting ideas which together will be developed further into a new and comprehensive communication strategy as part of our overall 2020/2021 aims.

Plans were in place to hold an event in September 2020 on a similar, though smaller, basis to our highly successful Anniversary Festival, however, these plans have been altered for the moment due to the current situation with Covid-19. We now plan to hold a virtual event in September 2020 and will postpone the planned face-to-face event until 2021.

The British Porphyria Association

Trustees' Annual Report *(continued)*

Year Ended 31 March 2020

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

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 1/7/20 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 2020

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 2020.

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').

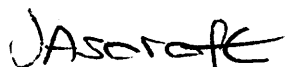
I report in respect of my examination of the charity's financial statements carried out under section 145 of the 2011 Act and in carrying out my examination I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

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 2020

		Unrestricted funds £	2020 Restricted funds £	Total funds £	2019 Total funds £
Income and endowments					
Donations	4	23,023	32,866	55,889	20,813
Investment income	5	38	42	80	82
Total income		<u>23,061</u>	<u>32,908</u>	<u>55,969</u>	<u>20,895</u>
Expenditure					
Expenditure on charitable activities	6,7	23,013	31,878	54,891	29,239
Total expenditure		<u>23,013</u>	<u>31,878</u>	<u>54,891</u>	<u>29,239</u>
Net income/(expenditure) and net movement in funds		<u>48</u>	<u>1,030</u>	<u>1,078</u>	<u>(8,344)</u>
Reconciliation of funds					
Total funds brought forward		24,262	15,620	39,882	48,226
Total funds carried forward		<u>24,310</u>	<u>16,650</u>	<u>40,960</u>	<u>39,882</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.

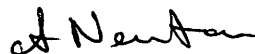
The British Porphyria Association

Statement of Financial Position

31 March 2020

	Note	2020 £	2019 £
Current Assets			
Debtors	12	385	–
Cash at bank and in hand		40,815	40,122
		<u>41,200</u>	<u>40,122</u>
Creditors: amounts falling due within one year	13	<u>240</u>	<u>240</u>
Net Current Assets		<u>40,960</u>	<u>39,882</u>
Total Assets Less Current Liabilities		<u>40,960</u>	<u>39,882</u>
Net Assets		<u>40,960</u>	<u>39,882</u>
Funds of the Charity			
Restricted funds		16,650	15,620
Unrestricted funds		<u>24,310</u>	<u>24,262</u>
Total charity funds	14	<u>40,960</u>	<u>39,882</u>

These financial statements were approved by the board of trustees and authorised for issue on ~~28.06.20~~, 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 2020

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 2020

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 2020

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

	2019-20		
	Unrestricted Funds £	Restricted Funds £	Total Funds 2020 £
Donations			
Donations and subscriptions	19,638	–	19,638
Gift aid	385	–	385
Grants			
Alnylam grant for festival	–	31,226	31,226
Alnylam 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>
	2018-19		
	Unrestricted Funds £	Restricted Funds £	Total Funds 2019 £
Donations			
Donations and subscriptions	18,171	2,000	20,171
Gift aid	642	–	642
Grants			
Alnylam grant for festival	–	–	–
Alnylam travel grant	–	–	–
Clinuvel Pharmaceuticals grant	–	–	–
	<u>18,813</u>	<u>2,000</u>	<u>20,813</u>

The British Porphyria Association

Notes to the Financial Statements (continued)

Year Ended 31 March 2020

5. Investment Income

	Unrestricted Funds £	Restricted Funds £	Total Funds 2020 £
Bank interest receivable	<u>38</u>	<u>42</u>	<u>80</u>
	Unrestricted Funds £	Restricted Funds £	Total Funds 2019 £
Bank interest receivable	<u>51</u>	<u>31</u>	<u>82</u>

6. Expenditure on Charitable Activities by Fund Type

	Unrestricted Funds £	Restricted Funds £	Total Funds 2020 £
Costs of charitable activities	<u>23,013</u>	<u>31,878</u>	<u>54,891</u>
	Unrestricted Funds £	Restricted Funds £	Total Funds 2019 £
Costs of charitable activities	<u>27,239</u>	<u>2,000</u>	<u>29,239</u>

7. Expenditure on Charitable Activities by Activity Type

	Activities undertaken directly £	Grant funding of activities £	Total funds 2020 £	Total fund 2019 £
Costs of charitable activities	<u>53,916</u>	<u>975</u>	<u>54,891</u>	<u>29,239</u>

8. Analysis of Grants

	2020 £	2019 £
Grants to Individuals		
Travel bursaries	975	124
Other grants	<u>—</u>	<u>200</u>
	<u>975</u>	<u>324</u>
Total grants	<u>975</u>	<u>324</u>

9. Independent Examination Fees

	2020 £	2019 £
Fees payable to the independent examiner for: Independent examination of the financial statements	<u>240</u>	<u>240</u>

The British Porphyria Association

Notes to the Financial Statements (continued)

Year Ended 31 March 2020

10. Staff Costs

The average head count of employees during the year was Nil (2019: Nil).

No employee received employee benefits of more than £60,000 during the year (2019: Nil).

11. Trustee Remuneration and Expenses

There were no trustees' remuneration or other benefits for the year ended 31st March 2020 nor for the year ending 31st March 2019.

During the year 3 trustees were reimbursed expenses totalling £3,044 (2019 - 4 trustees reimbursed £2,115).

12. Debtors

	2020	2019
	£	£
Gift aid receivable	385	—

13. Creditors: amounts falling due within one year

	2020	2019
	£	£
Accruals and deferred income	240	240

14. Analysis of Charitable Funds

Unrestricted funds

	At 1 April 2019 £	Income £	Expenditure £	At 31 March 2020 £
General funds	24,262	23,061	(23,013)	24,310

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

The British Porphyria Association

Notes to the Financial Statements (continued)

Year Ended 31 March 2020

14. Analysis of Charitable Funds (continued)

Restricted funds

	At 1 April 2019 £	Income £	Expenditure £	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>16,650</u>

	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	–	2,000	(1,800)	200
Alnylam travel grant	–	–	–	–
	<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.

15. Analysis of Net Assets Between Funds

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

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

The British Porphyria Association

Management Information

Year Ended 31 March 2020

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

The British Porphyria Association

Detailed Statement of Financial Activities

Year Ended 31 March 2020

	2020 £	2019 £
Income and endowments		
Donations		
Donations and subscriptions	19,638	20,171
Gift aid	385	642
Alnylam grant for festival	31,226	–
Alnylam travel grant	1,640	–
Clinuvel Pharmaceuticals grant	3,000	–
	<u>55,889</u>	<u>20,813</u>
Investment income		
Bank interest receivable	80	82
	<u>80</u>	<u>82</u>
Total income	<u>55,969</u>	<u>20,895</u>
Expenditure		
BPA events	1,706	7,538
Festival costs	21,856	–
Trustees' travel expenses - Festival	746	–
Committee travel costs - Festival	1,190	–
Insurance	720	627
International conference fees	1,082	–
Trustees' ordinary travel expenses	2,298	2,115
Ordinary travel expenses	4,876	2,949
Accountancy fees	240	240
Storage fees	515	386
Printing, postage, stationery and telephone	1,288	1,639
Newsletter	1,543	879
Advertising and promotional goods	45	1,042
Subscriptions	454	472
IT and software	233	217
Fundraising	1,117	480
Sundry costs	373	116
Administration fees	9,152	10,539
Administration fees - Festival	5,457	–
	<u>54,891</u>	<u>29,239</u>
Total expenditure	<u>54,891</u>	<u>29,239</u>
Net income/(expenditure)	<u>1,078</u>	<u>(8,344)</u>
