



THE BRITISH PORPHYRIA ASSOCIATION

Chairman's Report

The 2019-20 year was a year of great things for the BPA. Our festival event in October 2019, held at the Science and Industry Museum, Manchester, was a huge success and was attended by 169 people of all ages. With a diverse content we managed to engage and support those affected by porphyria as well as family members and others. We also held our first patient conference in Ireland in June 2019 with a total of 44 people attending from all over Ireland.

Internationally, BPA committee members attended and contributed to the International Congress on Porphyrins and Porphyrins (ICPP) in Milan in September (a scientific meeting supported by a patient day). The BPA showed leadership in the setting up and running of the Global Patient Advocacy Coalition (GPAC), as well as involvement in the European Porphyria Network (EPNET).

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

- bring volunteers into the charity with specific skills
- 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.

In line with one of our aims, we have a newly formed sub-committee – the Fundraising, Awareness and Social Media Working Group, which aims to increase our presence on social media platforms, and ensure we are fully engaged across all age groups. This is in addition to the Event Working Group, which started while organising the festival.

I'm very pleased to announce that Natassja Chadwick has volunteered to take on the Treasurer role – welcome Natassja.

This enables Anne Newton to step back a little for a much deserved break after spending more than 10 years as the BPA Treasurer. Thank you Anne, for being an essential and dedicated member of the BPA committee for such an extended period of time.

Welcome

We'd like to formally welcome our Fundraising, Awareness and Social Media Working Group.

Natassja Chadwick, Alicia Cawthorne and Victoria Harrold, supported by existing committee members Sue Burrell, Karen Harris and Anne Newton, began their first task with a flourish through a wonderful Porphyria Awareness Week; they continued this momentum with the ACTIVE 21 summer campaign.

Their combined knowledge and experience, as well as their dedication and enthusiasm have had a hugely positive impact in a really short space of time and we can't wait to see what they've got planned next.



bRED
It's in our blood.

#bRED4Porphyria

Porphyria Awareness Week



2020 ANNUAL REPORT

www.porphyria.org.uk

helpline@porphyria.org.uk 0300 30 200 30

Registered charity: 1089609

Treasurer's Report

The accounts were examined by Jane Ascroft Chartered Accountancy Limited, Barnard Castle.

Account name	31 Mar 2020	1 Sept 2020
BPA General Funds	£24,310	£24,051
Helen Gibbs Fund (restricted to research into acute porphyrias)	£13,743	£17,191
BPA Light Protection Fund (restricted)	£1,645	£1,645
Festival 2019 (restricted)	£1,262	£1,302

Income for 2019-20 was £55,889 (including the festival grant). Charity funds were raised through donations, grants and monies received from sponsored fundraising events.

Expenditure for 2019-20 was £54,891 (including one-off festival costs). The competitive grant and one-off costs from the festival event are separated out in the figures below. Some festival costs were incurred before the 2018-19 year-end and were included in the 2019 accounts.

At the year-end (31 March 20), £1,262 remained in the Festival account and was being used to cover the costs of editing legacy video footage from the day. Separating out festival income and expenditure confirms that regular income and expenditure remains stable at around £25,000 per annum.

Travel bursaries in the year provided financial assistance to enable members to attend our events. A grant process is also available to assist members with individual needs such as window films or with additional costs due to their porphyria.

Administration costs have increased due to additional demands on us as a charity and efforts to increase engagement with young people using a variety of communication streams.

Other general expenses include postage, insurance, membership fees, producing and mailing newsletters, leaflet printing and merchandise.

Efforts continue to ensure that patients are represented in new drug approval and regulatory processes as well as maintaining international networks.

How your donations help

£5 covers the annual cost of the BPA newsletter (two issues) to one person

£15 funds the email and telephone helpline for a week

£50 enables us to keep a social media and website presence for a month

2019-20 FINANCES

Income

(excluding festival grant)

£24,663

Expenditure

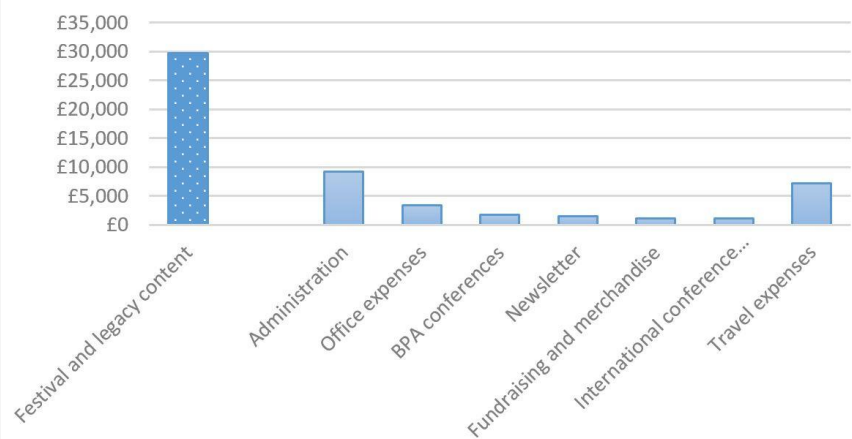
(excluding festival costs)

£25,188

2019-20 Income



2019-20 Expenditure



How we do it

Our amazing trustees, committee and working group members put in countless hours to support patients and keep the charity moving forwards.

For every paid hour that our administrators do, we conservatively calculate that our dedicated team put in at least three voluntary hours. So, our wonderful team is doing the work equivalent to three full-time staff members!

Paid hours 19-20 **1,496**
Voluntary hours 19-20 **4,488**