



THE BRITISH PORPHYRIA ASSOCIATION



Chairman's Report

The 2020-21 financial year was a strange and challenging time for everyone. However, with the help of our extended committee and friends, the BPA was able to continue.

Our main achievement in 2020 was to transform our usual in-person event to our first ever online event: Connect 2020 - a day-long series of presentations and interactive sessions for patients and families. Particular focus was placed on sessions that engaged young patients. Supported by medical experts and pre-recorded videos, expert panels offered advice in interactive sessions. The event was a huge success: 97% stated they would attend a similar event again and rated it 91/100 for how well it met expectations, and 91/100 for content.

Covid-19 heightened the feelings of isolation for many, amplifying the need for us to engage with patients and families in new ways, as well as continuing our usual work. We turned to social media to fuel engagement during porphyria awareness week (PAW), and were delighted that so many of you tuned in during this time, and took on the challenge of raising funds through our bRED campaign.

Throughout all of the lockdowns, our helplines continued to offer 1-to-1 support to help the porphyria community feel safe and connected. We are pleased that we managed to successfully adapt our services and communications at a time when patients felt most vulnerable and the NHS was stretched to its limit.

We have continued to represent porphyria patients in the regulatory field, most recently with NICE for Givosiran. Initially the medication was 'not recommended', but we now await the outcome from a second committee meeting, which we hope will be more positive for those severely affected acute porphyria patients.

In early 2021, we looked again at our strategic plan. In addition to continuing our themes of UNDERSTAND, CONNECT and TAKE CONTROL, we'd also like to:

- Focus on the mental health of people living with porphyria and facilitate some online sessions with a trained mental health and wellbeing 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.
- Seek a new treasurer as Natassja Chadwick had to step down due to a change in personal circumstances. Anne Newton has kindly stepped back in on a temporary basis, for which we are all extremely grateful.

Thank you all for your continued support and let's hope we can all meet again in 2022.

2021 ANNUAL AGM REPORT

We welcomed

40

new members in the
last year

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 2021	22 Sept 2021
BPA General Funds	£24,534	£21,174
Helen Gibbs Fund (restricted to research into acute porphyrias)	£17,195	£17,196
BPA Light Protection Fund (restricted)	£1,020	£1,020
Festival 2019 (restricted)	£1,264	£1,196

Income for 2020-21 was £25,650. Charity funds were raised through donations, grants and monies received from sponsored fundraising events.

Expenditure for 2020-21 was £22,597. At the year-end (31 March 21), £1,264 remained in the Festival account but has since reduced due to the costs of editing legacy video footage from the day.

The September 2021 balance includes a grant of £1,000 from The Albert Hunt Trust to help towards a mental health and wellbeing project. Expenses for the Christmas bauble fundraiser are still to be accounted for.

Despite the challenges of Covid, we managed to maintain a relatively stable level of income through diversifying fundraising streams, including the Porphyria Awareness Week bRED campaign and a successful Christmas bauble fundraiser.

A grant process is available to assist members with individual needs such as window films or with additional costs due to their porphyria. When face-to-face meetings return in 2022, we will re-start our travel bursary to enable accessibility to our events for all.

Administration costs remained consistent despite increased engagement through a variety of communication streams. Other general expenses include postage, insurance, membership fees, storage fees, producing and mailing newsletters, leaflet printing and merchandise.

2020-21 FINANCES

Income
£25,650

Expenditure
£22,597

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

What do we do?

The image shows how our two part-time (paid) administrators split their time and how the work supports our aims of EDUCATION, SUPPORT and RESEARCH. We are proud that 61% of their time goes directly towards two of our primary intentions to support patients and provide resources for education and greater awareness.

Despite our small size as a rare disease charity, we also manage to focus 11% of our resources on encouraging research and providing a patient perspective for new medications going through the regulatory process.

It is important not to forget our volunteers and the huge impact they have on our ability to function. Our Chair, Secretary and Treasurer – three primary roles in terms of charity management and finance – are volunteers, as are our other Trustees.

The rest of our dedicated volunteer committee work on many different areas of the charity's work, especially social media, merchandise campaigns, event planning and IT support.

Time allocation: paid administrators

