



HOW WE DO IT!

12

Committee including trustees and administrators

74

Paid hours per month

In 2018-19, BPA administrators were paid for an average of 74 hours a month

222

Estimated voluntary hours per month

BPA committee members put in countless voluntary hours every month, involving areas such as: finances, fundraising, new drug development, helplines, patient information, social media, websites, charity administration, as well as representing the porphyrias nationally and internationally.

ANNUAL REPORT 2019

The British Porphyria Association

Registered Charity 1089609

INTRODUCTION

Chairman, John Chamberlayne

It's 20 years since the formation of the BPA and we really have come a long way! From half a dozen strangers meeting informally for mutual support to a thriving charity with 345 members.

The 2018-19 year saw the BPA continue to develop and flourish in its activities. In June we had our first Open Day in Ireland. Despite losing some members due to GDPR in the last year or so, 2018 and 2019 brought 58 new members to our database. We now have about 300 families with porphyria, and 50 medical and pharmaceutical contacts

Our two-year strategy, updated in 2018, prioritised a focus on young people, while a new committee member helped move this forward by providing a younger perspective. The 20th Anniversary Festival has been designed to be immersive and engaging especially to the under 30 age group. It also aims to focus on the poorly met mental health and well-being needs of porphyria patients.

As well as general operations in running the charity, committee members have been highly involved in new drug development processes and the UK appraisal process for Scenesse. The BPA are also involved with clinician and patient networks, both national and international. This helps to bring vast benefits to patients and enables us to be more reactive and up-to-date with information we share with members. In particular we have been helping set up, and are heavily involved with, the new Global Porphyria Advocacy Coalition, linking patient organisations throughout the world.

As always, we are grateful to the many members who raise funds for the BPA, whether running, cycling or something completely different. I would also like to thank all our committee members for their hard work.

Today's festival is a great chance to celebrate our successes and thank our supporters and the people who have made this happen over the years. It is also a time to look at our areas for growth and take bold steps to keep moving forward to best serve our members for the next 20 years.

345
members

From humble beginnings...

"In 1998, I read a dreadful newspaper article about porphyria, which prompted me to write to the newspaper. Little did I realise then that we would be able to build such a fantastic charity, helping those with porphyria and their families. It was thanks to Prof Timothy Peters and Prof George Elder, who brought a group of us together to discuss how we could work towards a support group. And so, the BPA was founded, and here we are, 20 years later, known internationally for our work with patients, medical professionals, and drug institutions. We have a fantastic team, and I am so proud to still be a small part of this."

Karen Harris, Founding Member
Former Chairman and Current Trustee

When I got involved with the BPA 20 years ago, I never imagined it would turn into something so wonderful. I was just desperate for information as my daughter was so poorly.

Anne Newton, Treasurer, Trustee since 2001



FINANCES

2018-2019

£20,895

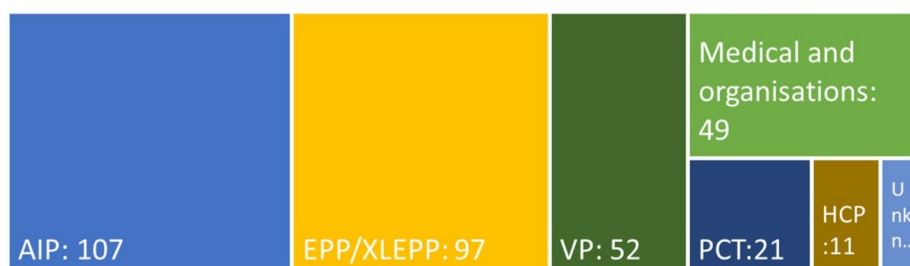
INCOME FROM DONATIONS,
FUNDRAISING AND GRANTS

£29,239

OPERATIONAL EXPENDITURE
AND GRANT MAKING

BPA MEMBERSHIP

- Medical and organisations: 49
- EPP/XLEPP: 97
- PCT:21
- CEP: 1
- AIP: 107
- VP: 52
- HCP:11
- Unknown: 7



TREASURER'S REPORT

Anne Newton

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

ACCOUNT NAME	31 MAR 2019	26 SEPT 2019
BPA General Funds	£24,502	£21,791
Helen Gibbs Fund (<i>restricted to research into acute porphyrias</i>)	£13,717	£13,731
BPA Light Protection Fund (<i>restricted</i>)	£1,701	£1,703
Festival 2019 (<i>restricted</i>)	£200	£25,184

Income for 2018-2019 was £20,895. Charity funds were raised through donations, grants and monies received from sponsored fundraising events. Later in 2019, we received grants from Recordati (formerly Orphan Europe), Clinuvel (UK) Ltd and Alnylam Pharmaceuticals.

Expenditure for 2018-2019 was £29,239. This was expected, as some festival expenses were payable before the agreed grants reached us in the 2019-20 financial year.

Administration costs have increased due to additional demands on us as a charity. Other general expenses include postage, insurance, membership fees, producing and mailing newsletters, leaflet printing and merchandise. Expenses also cover attendance at committee and other relevant meetings and the putting on of our annual events.

Funds are made available to assist members who require financial assistance to enable them to attend our events. Funds are also available, on a discretionary basis, to assist members with individual needs such as window films or with additional costs due to their porphyria.