



The British Porphyria Association

136 Devonshire Rd
Durham City
County Durham
DH1 2BL
Charity No: 1089609
www.porphyria.org.uk
0300 30 200 30

Privacy policy

At the British Porphyria Association (BPA), we're committed to protecting and respecting your privacy. This policy explains when and why we collect personal information.

Who are we?

The British Porphyria Association is a registered charity (no. 1089609). The registered address is 136 Devonshire Road, Durham City, DH1 2BL.

When do we collect information?

We obtain information about you when you contact us via the email or telephone helpline, when you make a donation, when you fundraise or volunteer for us, or if you become a member.

What type of information is collected?

The personal information we collect might include your name, address, email address, telephone number and type of porphyria. We are also legally required to collect financial information relating to donations and subscriptions.

How is your information used?

We may use your information to:

- communicate with you about events, send information that you have requested or that may be of interest to you
- help respond to your queries
- process a donation that you have made
- support you as a fundraiser or volunteer
- seek your views or comments on the services we provide
- notify you of changes to our services.

We review the length of time we keep personal information on a regular basis. We are legally required to hold some types of information to fulfil our statutory obligations (for example, the collection of Gift Aid). We only hold personal information on our systems for as long as is necessary.

Who has access to your information?

Only relevant members of the BPA committee that need to process, monitor or audit personal data will have access to your information. In certain instances, your information may be accessed by reputable third parties to process BPA services, such as sending out newsletters.

We will never sell or rent out your information to third parties and we promise to keep your details safe and secure.

Your choices

You have a choice about whether or not you wish to receive information from us as well as how you would like to receive that information. You can change your mind or update your details at any time. Please contact us on helpline@porphyria.org.uk or 0300 30 200 30.



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Find out what information we hold about you

You have the right to ask for a copy of the information we hold about you. Please contact us on helpline@porphyria.org.uk or 0300 30 200 30.

Remove all information about me

You have the right to ask for all information we hold about you to be removed. (This excludes some financial records that we are legally obliged to keep for a certain length of time, for example, Gift Aid forms). Please contact us on helpline@porphyria.org.uk or 0300 30 200 30 to remove your information.

Security of your information

Security precautions are in place to protect the loss, misuse or alteration of your information.

While we strive to protect your personal information, we cannot guarantee the security of any information you transmit to us, and you do so at your own risk. Once we receive your information, we make our best effort to ensure its security on our systems.

Use of 'cookies'

Like many other websites, the BPA website uses cookies. 'Cookies' are small pieces of information sent by an organisation to your computer and stored on your hard drive to allow that website to recognise you when you visit. They collect statistical data about your browsing actions and patterns and do not identify you as an individual. It is possible to switch off cookies by setting your browser preferences.

Children

We are concerned to protect the privacy of children. If you are aged 13 or under, please get your parent/guardian's permission beforehand whenever you provide us with personal information. Any child over the age of 13 can make decisions about their own data without consent of their parents.

Information Commissioner's Office

If you have a concern about the way we are collecting or using your personal data, we request that you raise your concern with us in the first instance. Alternatively, you can contact the Information Commissioner's Office:

- Report a concern online at <https://ico.org.uk/concerns/>
- Call 0303 123 1113
- Or write to: Information Commissioner's Office, Wycliffe House, Water Lane, Wilmslow, Cheshire, SK9 5AF

Review of this policy

We keep this policy under regular review. This policy was last updated May 2020.

Signed: *J Chamberlayne* NameJohn Chamberlayne.....

Position:BPA Chair.....