



British Porphyria Association

Charity No: 1089609 0300 30 200 30 www.porphyrria.org.uk
136 Devonshire Road, Durham City, DH1 2BL



Sponsorship pack

2017



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Thank you for contacting the BPA.

We are delighted that you are planning to raise funds for us. We understand that you have an event already planned and so you might find this pack helpful. Within this sponsorship pack, we have included:

- Details of where to send funds
- Details on setting up a JustGiving webpage to help raise your funds
- Information on what the BPA does (which you can use to help your fundraising efforts)
- Sponsorship form

Thank you from the BPA

The BPA would like to thank you in advance for your drive to raise funds for us; your fundraising activities are greatly appreciated and as a little thank you, if you are planning on raising more than £50, we will send you a BPA t-shirt. You can wear this to help increase awareness or for during your event (sometimes it is the supporters that wear them) – just let us know the size that you would like and where you would like it sending and we will get it posted out to you.

If you are doing an athletic or endurance event (e.g. marathon, triathlon or cycling event) we also have a few professional grade sports jerseys that are much more comfortable to wear. If you are planning on raising more than £150 for the BPA, we may be able to send you one of these sports jerseys. It is a great way to increase awareness, just let us know the size you require (you may like to ask for a larger size as they come up as a small/slim fit).

Many thanks again, and we wish you the very best of luck with your event.

Kind regards

John Chamberlayne (on behalf of the whole BPA committee)

Sending funds to the BPA

You can choose to donate funds to either of the following areas, if you decide to send funds directly to the bank, it is vital that you also send an email to treasurer@porphyria.org.uk to explain what funds you have deposited and who they are from/what they relate to.

BPA general funds	Light protection fund
This account is used to run the charity on a day-to-day basis, covering bills, printing costs, newsletters, events, travel, stationery, etc.	This account was set up to generate funds for light protection for people with cutaneous (skin) porphyrias.
Sort code: 20-43-63 Acc. No: 7099 6904	Sort code: 20-43-63 Acc. No: 1352 6453
Text TBPA14 £*** to 70070	Text LTBX14 £*** to 70070

Alternatively, please send cheques to the BPA Treasurer: Rothlea House, 7-8 Quarry Lane, Butterknowle, Bishop Auckland, County Durham, DL13 5LL.

We ask that funds are paid to us within 28 days of the event occurring.

JustGiving

It is easy to set up a JustGiving webpage, for all of your friends and family to sponsor your event, and you can update it regularly with your progress which helps to keep people interested. You can do this here: <http://www.justgiving.com/britishporphyriaassoc>.



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About the BPA

The British Porphyria Association (BPA) was established in 1999 by a group of patients and relatives who had experienced isolation and difficulties due to a general lack of understanding in diagnosing and treating their conditions. The BPA became a registered charity in 2001 and is run by a committee of volunteers.

What does the BPA aim to do?

The BPA aims to reach out to as many people as possible in order to improve the understanding of the different porphyria conditions for:

- The patients and relatives
- The doctors and medical staff
- The hospitals and research establishments

The porphyrias are a group of rare conditions which are often portrayed in a dismal light. Although the disorders can in some cases be very severe, there are many reasons to be optimistic, and with the right information, many sufferers can live absolutely normal lives. Early diagnosis is vital if we are to improve the quality of life for those affected by it.

- The BPA's primary aim is to improve understanding of the condition, raising awareness and ensuring that the portrayal is always accurate.
- The BPA raises funds in order to educate patients and their families about their condition.
- The BPA aims to provide an emotional support system for sufferers and their families and provides contacts with doctors and specialists.
- The BPA aims to facilitate understanding for doctors and other healthcare professionals.
- The BPA raises funding for new research into the field of porphyria and encourages new research projects.
- We provide information and vital support to our patients, providing a telephone and email helpline, a newsletter, open days, conferences and patient meetings. We help with medical research projects and push forward with education for patients and their families, as well as education for medical staff.

What are the porphyrias?

The porphyrias are a group of eight relatively rare genetic disorders. In each porphyria a specific enzyme needed to complete a step in the pathway to produce haem (a necessary element of blood), is faulty. Porphyrins accumulate causing severe medical problems. The type of porphyria varies according to the enzyme which is affected. The porphyrias are broadly divided into acute and cutaneous (skin), although some porphyrias suffer from both sets of symptoms (VP and HCP). The severity of symptoms varies dramatically in all types of porphyria. For the skin porphyrias they experience extreme sensitivity to sunlight and visible light which can vary from sensitivity and burning to severe blistering and scarring. For the acute porphyrias severe pain, paralysis and sickness can be experienced when in an acute attack. Hospitalisation is usually required to treat attacks of the acute porphyrias in order to monitor and treat the patient's condition. But no matter which type, the more knowledgeable about their condition a patient is, the more they are likely to stay well.

