



British Porphyria Association

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



Fundraising Pack



2017



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Thank you for contacting the British Porphyria Association (BPA).

We are delighted that you are planning to raise funds for us. We understand that you either have a fundraising event already booked or are in the process of planning an event and we would like to offer you as much support as you need to raise your funds.

Within this fundraising pack, we have included:

- Fundraising guidelines (these are very IMPORTANT – please read)
- BPA merchandise information
- Details on setting up a JustGiving or Virgin Money Giving webpage to help raise your funds
- Details of where to send funds
- Information on what the BPA does (which you can use to help your fundraising efforts)
- Fundraising ideas
- 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).

Please do let us know if you would like a t-shirt or any of the other merchandise items ordering.

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)



Fundraising Guidelines

Introduction

The aim of these guidelines is to help you to organise a fundraising event or activity that is safe and legal, as well as enjoyable. Please take the time to read this important information and do not hesitate to contact us if there is any other way we can help: helpline@porphyria.org.uk or 0300 30 200 30.

Please remember that you are responsible for taking adequate steps to ensure that the event poses no risk to others. The BPA cannot accept liability for any loss, damage or injury suffered by you or anyone else as a result of taking part in a fundraising event.

Useful tips

- Keep ideas simple – a quiz night or a football tournament can be very effective.
- Decide when the event should be – will it clash with any other local or national event?
- Decide on a venue – do you need disabled access/good parking/transport links?
- Set a fundraising target and an expenses budget.
- Plan the event carefully, working out a timetable and sticking to it.
- Ask friends and family to help and assign them specific tasks or responsibilities.
- Draw up a list of equipment and/or catering needs.
- Decide how you will publicise your event (see next page).
- Decide whether you need to have a bad weather plan.
- Check what safety and legal requirements there might be (see next section).
- Ask local suppliers if they can donate supplies or goods, or provide discounts.
- Approach your workplace to see if your company will match your fundraising total or make a contribution.

Simple fundraisers

Simple fundraisers, such as sponsorship for a fun-run or a dress-down day at work, take little organising and don't involve much in the way of legal rules. (Except ensuring that any funds raised 'in aid of the BPA' are sent to us!)

There is a sponsorship form at the back of this pack, and you are welcome to photocopy it as needed. Also, see the section on the next page about Just Giving.

A dress-down day can be a good fundraiser, but please make sure it has been agreed with your manager.

A coffee morning at home is also easy to arrange, and could include the sale of home-made cakes. Please make sure anyone handling food washes their hands or wears sterile gloves. We would not recommend advertising an event such as this, stick to inviting neighbours and friends, or you might get unwelcome guests.

If you need to use our logo on anything, please see the later section for details on how to do this.



Publicising your event

Advertising

It is important to publicise your event to make a success of all your hard work. For any event, challenge or any fundraising activity, you could try some or all of the following:

- **Poster and flyers:** are great for promotion and the more eye-catching the better. Display your posters on notice boards in coffee shops, libraries, schools, sports centres, office blocks, village halls – anywhere you can find, but please ask permission first. Make sure they include the essentials details of the event – What? Where? When? Who? Include your contact details and/or details of where they can sponsor you.
- **Social media and the internet:** Facebook and Twitter are quick, easy and effective ways of reaching lots of people very quickly, you can also keep people updated about how the event is coming together. Tell us about your event and we will also add it to the upcoming events page of our BPA website.
- **Media coverage:** contact your local media and send them details before and after your event (including good quality photos if you have them).

JustGiving & Virgin Money Giving

It is easy to set up a JustGiving or Virgin Money Giving 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> or here: <http://uk.virginmoneygiving.com/charity-web/charity/finalCharityHomepage.action?charityId=1011046>

Using the BPA logo and printed materials

We are happy to provide an electronic copy of the BPA logo, which must be used in its complete form and not altered. It is important to also include the Registered Charity No. 1089609 on any material produced. ***Please ensure that all printed material that includes our logo is forwarded to us for approval prior to printing.***

To comply with charity law, it is vital that printed materials clearly state how the funds raised are to be donated. If all proceeds are to be donated, wording should state that your event is ***'in aid of the BPA'***. Otherwise, it is important to say exactly how the BPA will benefit (e.g. for every ticket sold £1 will be donated to the BPA).

Lotteries, raffles and tombolas: rules and regulations

These types of activities are great for fundraising, but they are also regulated by law, so if you plan to use them, it is important that you read and understand the following guidelines.

Lotteries, raffles and tombolas are games of chance where people pay for an opportunity to win a prize or money. Some events, such as duck or balloon races, are also covered by lottery laws.

If an element of skill is introduced, it becomes a competition and there are fewer restrictions.

There are many types of lottery that can be run ***'in aid of the BPA'*** very easily. For the first two, you do not need any licences. Make sure you note contact details of buyers on the ticket stubs, in case they aren't around when you do the draw.

- **Incidental non-commercial lottery:** This refers to a lottery/raffle/tombola that takes place during an event (e.g. fete, fun day, dinner dance). All tickets must be sold during the event and results announced the same day (at the event). No more than £100 may be deducted from proceeds to cover expenses (e.g. printing tickets) and £500 to cover prizes (does not include donated prizes). Tickets must all be the same price. No rollovers. Money raised at the event, such as entrance fees must go entirely to purposes that are not for private gain.
- **Private lottery:** For private lotteries, only members of a society/club/workplace and people on those premises can take part. Tickets cannot be sold to the general public or advertised



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externally. There are no limits on sales or prizes. The promoter must be a member of the organisation or workplace. Tickets must show the price, the name and address of the promoter, and who is eligible to take part. Tickets must all be the same price and must be paid before entering the draw. No rollovers allowed.

- **Small society lotteries:** These raffles are open to the public and tickets can also be sold in advance; they must be registered with your local authority. A named promoter must take responsibility. If you wish to run this type of activity, please contact the BPA for further advice.

Major events

Charity fundraising is regulated by law and so it is important that all parties comply with any legal requirements. If you are expecting large numbers of members of the public to an event, you are likely to need to do the following:

- Contact the police
- Contact the local council for permits
- Ask St John's Ambulance for first aid advice
- Check whether public liability insurance is needed – events run by you *'in aid of the BPA'* are not covered by the BPA's public liability insurance
- Undertake a fire risk assessment
- Consider security risks
- Consider health and safety risks

You (may) also need to:

- Consider provision of toilets, drinking water, washing facilities and/or disposal of rubbish
- Ensure that any sub-contractors have the required experience and insurances
- Obtain any relevant licences/permits from local authorities, e.g. alcohol or music
- Ensure any paper or electronic records you keep about people involved in the event comply with the Data Protection Act requirements.

BPA merchandise

We have various items of BPA merchandise that you may buy/sell to raise funds and awareness. If you would like any of these items, they cost the following (plus £1.00 p&p):

- BPA wristbands (in red, in adult and child sizes) - £2.00 each
- EPP wristbands (in purple, in adult and child sizes) - £2.00 each
- BPA pin badges (of our logo) - £2.00 each
- BPA torch key rings (with our logo on) - £2.00 each
- BPA pens - £2.00 each
- BPA propelling pencils - £2.00 each
- BPA canvas bags - £3.50 each
- BPA t-shirts (in various sizes) - £7.00 each
- BPA running vests – available upon request - £30.00 each
- BPA cycle jerseys – available upon request - price TBC

We are also happy to provide you with a merchandise pack and display box if you would like to sell merchandise for us, for example at a school fete. We ask for a deposit of £20 to obtain one of these kits as the merchandise within it will be valued at around £100. You can then sell the merchandise at your event on a sale or return basis, and send us the remaining merchandise and the proceeds (less your deposit) at the end.



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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 and is needed to pay bills, printing costs, newsletters, educational events, travel, stationery, etc.	This account was set up to generate funds for light protection projects for people with cutaneous porphyria, e.g. window films for those with EPP
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.



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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, it was run solely by a committee of volunteers until March 2015 when a 'paid' administrator was appointed to work 6 hours a week to meet our members' needs.

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.



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Fundraising ideas

A

- Abseil
- Aerobics: sponsored marathon/competition
- Antiques fair
- Arts or crafts stall/exhibition/fair
- Auctions

B

- Baked beans bath
- Barbecue
- Barn Dance
- Bike rides
- Bits and Pieces (music quiz)
- BMX bike display, or competition
- Book/comic sale
- Boot sale
- Bouncy castle – it could be a sponsored event, e.g. number of bounces per minute!
- Bring and buy sale

C

- Cabarets/talent shows
- Car boot sale
- Car washing
- Card delivery service, pupils pay for delivery within the school
- Cards and gifts
- Carol singing
- Charity shop – open one lunchtime a week selling donated items
- Christmas cards – making and selling them, or selling bought cards
- Class collections
- Coffee mornings
- Collections of money at speech day
- Collections of other things (e.g. waste paper, bottle tops, coins, stamps)
- Competitions
- Computer games knockout, best if played in pairs
- Concerts/recitals/plays/shows
- Cook books – writing a class or school cookbook that can then be sold
- Cookery contest (e.g. Ready Steady Cook!)

D

- Dance marathon
- Dinner dance/ball
- Discos/raves
- Donkey Derby
- Dragon boat race
- Dry Cornflakes/Cream Cracker-eating contest



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E

- Easter egg hunt
- Easter party
- Egg rolling competition
- Ebay for Charity (BPA)

F

- Face painting
- Fairs, fetes, bazaars, etc
- Fancy dress party/day
- Fashion show (with clothes made by pupils or donated by local shops)
- Fifty to One
- Film show/premiere
- Fireworks party (adults to organise)
- Flower/fruit/vegetable show/sale/display/stall
- Foam party – fill paddling or swimming pool with foam and then party!
- Football tournament

G

- Game shows (e.g Stars In Their Eyes, Wheel of Fortune, Blockbusters, Blind Date etc)
- Gigs (local bands play in school)
- Gladiators
- Go-Karting
- Golf day
- Gymkhana
- Great Run Series (North, South etc)

H

- Hair beading/plaiting
- Halloween party
- Hot-dog/burger stand

I

- It's a Knockout competition

J

- Judo competition or display (adults to organise)
- Jumble sale

K

- Karaoke competition/display (adults to organise)
- Kite flying

L

- Line dancing
- London Marathon
- Longest chain of paper-clips, line of coins, etc
- Lottery – can be Choco Lotto where numbers are put onto sweet packets



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M

- Man O Man (or Teacher O Teacher)
- Marathon events – table tennis, aerobics, line dancing, badminton, etc.(in shift teams)
- Midsummer masked ball
- Midnight film shows/parties/etc
- Mufti/non-uniform/denim/tracksuit/etc.day
- Murder Mystery evening

N

- New Year's Eve dance/party
- Night-time hide and seek, using torches
- No work day, students choose what they want to do

O

- Old-time music hall
- One hundred club – raising £100 every week, half term or term, or a fundraising club with 100 members in it
- Open House

P

- Pamper/alternative therapies evening
- Pancake day race/competition
- Panel games
- Parachute jump
- Parties – school birthday/anniversary, etc.
- Penalty shoot-out competition
- Penny mile, where coins are lined up and measured – can be done in teams
- Pet show
- Photographic competitions
- Pram push

Q

- Quizzes

R

- Races
- Raffles (see guidelines)
- Rapping contest, show or sponsored event
- Running events

S

- Saints' days parties/theme day
- Santa's grotto
- School fair
- Scoff-a-hotdog competition (e.g. 'who can eat two in the fastest time possible'!)
- Shakespeare marathon
- Silly games afternoons: egg & spoon, silly races, wet sponge throwing, etc
- Skateboard display
- Slide evening



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- Soap episodes show or theme day
- Sponsored events (e.g. bike ride, dog walk, knit, kite-flying, head shave, haircut, hula-hooping, no smoking, rapping, run, shoe-clean, silence, sing, sports match, swim, talk, three-legged walks, walk, watch TV/don't watch TV, window clean, etc.)
- Sports contests, teachers vs students (no PE teachers allowed!)
- Stalls at fairs etc.(e.g. cakes, plants, books)
- Strawberry and cream tea party
- Student-teacher swap day
- Swap-shop

T

- Tea party
- Teddy bears' picnic
- Theme days/evenings (e.g countries – French, Spanish; soap operas, past-eras etc)
- Throwing wet sponges at a person/teacher in stocks, great at a summer fair!
- Tombola
- Top of the Pops show, teachers or students miming and dancing to chart music
- Treasure hunt
- Treks
- Tuck shop

U

- Uniform days (for schools without a uniform and/or for teachers)
- University challenge

V

- Variety show

W

- Wacky Races
- Whist drive
- White Elephant stall
- Who's that baby? (students and staff bring in photos of themselves as babies)
- www.buy.at/BPA

X

- X-Files day (Use your imagination – the ideas are out there!)
- Xmas fair/panto/party

Y

- Yacht race, etc
- Young Enterprise Scheme run by students, donate part of profits (e.g. making and selling cards)

Z

- Zany parties

