



The Campaign #PorphyriaTogether

**Dates** 2-9 April 2022

Hashtags #PorphyriaTogether

#PAW2022

#PurpleForPorphyria

#Tell15

### Purple for porphyria – Friday 8 April 2022 #PurpleForPorphyria Let's join together to colour the globe Purple For Porphyria

Why not help us raise awareness and funds for the BPA? You could choose one of the following **#PurpleForPorphyria** options that are easy to organise at work/school.

Remember: We are a strong porphyria community, you are not alone, we are #PorphyriaTogether

### Step-by-step guide: Purple for porphyria

### STEP 1: Choose one of the following three options

- 1. **Wear purple for porphyria.** Get your children and their school and/or your workplace/friends/community or even your local hospital involved in **Purple for porphyria.** If the Friday won't work, choose any day of PAW!
- 2. **Wear purple for porphyria and ask for a donation.** Why not ask for small donations from work colleagues/school children to wear purple and raise some funds for the BPA too?
  - Funds can be paid to:

**British Porphyria Association** 

Sort code: 20-43-63, Account no. 7099 6904

Please use your name and PAW and postcode as the payment reference.

3. Wear purple, raise funds and host an awareness event. Why not organise a porphyria film viewing to #Tell15 other people about porphyria? See the 'Organise a viewing guideline' PDF for more information on some amazing films you could share on your #PurpleForPorphyria day!

### **STEP 2: Organise your Purple for porphyria day**

- 1. Contact the venue (sample email below)
- 2. Choose a date (if not Friday 8 April)
- 3. Edit and send the flyer/poster below to people involved in Purple for porphyria day
- 4. Collect funds
- 5. Organise a film viewing if desired (#Tell15)
- 6. Share images via social media, of what you have been getting up to

### STEP 3: Take a photo of your day and email this to the BPA

1. Send photos to <a href="mailto:helpline@porphyria.org.uk">helpline@porphyria.org.uk</a>

Tips for taking photos of your activities/efforts:

- A clear/nice background (indoors or outdoors) and a well-lit area
- A clean camera/phone lens

# Template email to school or work [adapt as you see fit] Dear ... I hope this email finds you well. [I am/My family member are] affected by a rare condition called porphyria. Porphyria is a group of conditions that affect [insert details of the porphyria affecting you/your family – more details on <a href="http://porphyria.org.uk/what-is-porphyria/">http://porphyria.org.uk/what-is-porphyria/</a>].... The British Porphyria Association (BPA) is a UK charity which supports patients and the families affected by porphyria. They are involved in a global campaign, each year, to raise awareness of porphyria during Porphyria Awareness Week (2-9 April 2022).

I would like to get involved with a PurpleForPorphyria day and [wear purple and raise funds for the BPA – by asking people for small donations to the BPA/wear purple, ask for small donations to the BPA and show an awareness video to explain more about how [insert name] is affected by porphyria] and am hoping we can do this at [work/school] to help raise awareness of porphyria.

I would like to do this on Friday 8 April – or another suitable date between the 2 and 9 April. The overarching theme of PAW this year is the importance of awareness and being a strong community, in the form of #PorphyriaTogether.

Please can you let me know, if you would be happy for [insert name of environment, school, workplace] to be involved.

Very much looking forward to hearing from you and hopefully planning a 'PurpleForPorphyria' day with your support.

With best wishes



On Friday, April 8 – Let's join together to color the globe Purple for Porphyria



### Please join us and WEAR PURPLE

## To raise awareness and funds for the British Porphyria Association

Cash donations to...