Dear …

I am writing with support from the British Porphyria Association (BPA) – a small national charity which supports porphyria patients and their families, across the whole of the UK and Ireland.

The porphyrias are a group of rare conditions as they affect a small number of the population[[1]](#footnote-1). But, the complexities of the porphyrias mean that patients often experience exceptionally negative effects on all aspects of their lives!

The BPA encourages patients and families to be informed and educated about their condition, to connect with others and share their stories so that they are more able to take control and be empowered patients.

**How can your school/organisation help?**

**Get involved with #SpotlightPorphyria or #PurpleForPorphyria**: I [insert pupil/employee name] would like to raise awareness of the porphyrias and the work the BPA do by arranging one/two **Wear #PurpleForPorphyria** day(s) at [insert school/organisation here] on:

* Rare Disease Day - Thursday 29 February 2024
* Porphyria Awareness Week – Anytime between 11-18 May 2024
* Global Porphyria Day – Saturday 18 May 2024 [[2]](#footnote-2)

The BPA has the following resources (downloadable from their website from Nov 23) to support any efforts:

1. Template letter to parents – asking for a £1.00 donation to Wear Purple for Porphyria to raise awareness of porphyria – detailing how to donate and what donations will contribute to.
2. Details of ways to collect donations.
3. Posters for your newsletter/social media/comms channels, etc., to promote the event.
4. Age appropriate awareness videos to be played at school/work to **Spotlight Porphyria: Re-think Rare – Think Porphyria**

Thank you for taking the time to read this letter – I really would be very grateful if you can help support the BPA in the campaign to raise awareness of porphyria as a rare condition within [insert school/work/local community].

Please let me know if you would be happy for [insert name of environment, school, workplace] to be involved? I’m very much looking forward to hearing from you and hopefully planning a **Purple for Porphyria** **Day** with your support. I can be contacted on [insert contact number/email].

With best wishes

 [insert name]

1. www.porphyria.org.uk [↑](#footnote-ref-1)
2. This may not work well within a work/school environment in 2024, with the date falling on a weekend, so another date between 11-18 May might work instead. [↑](#footnote-ref-2)